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Recognizing that Children with Disabilities are Children First

A Study on the Situation of Care and Protection of Children with Disabilities in India

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For more information, please write to info@khsia.org.

LIST OF ABBREVIATIONS

AAC	Alternative and Augmentative Communication
ADIP	Assistance to Persons with Disabilities for Purchase/Fitting of Aids/Appliances
AIIMS	All India Institute of Medical Sciences
ANM	Auxiliary Nurse Midwife
ASHA	Accredited Social Health Activist
ASTHA	Alternative Strategies for the Handicapped
AYJNISHD	Ali Yavar Jung National Institute of Speech and Hearing Disabilities
CAFT-India	Children and Families Together - India
CBID	Community Based Inclusive Development
CBR	Community Based Rehabilitation
CCI	Child Care Institution
CINI	Child in Need Institute
CIP	Central Institute of Psychiatry
CMHA	Central Mental Health Authority
CRC	Convention on the Rights of the Child
CRPD	Convention on the Rights of Persons with Disabilities
CWC	Child Welfare Committee
CWSN	Children with Special Needs
DoEPwD	Department of Empowerment of Persons with Disabilities
DCPU	District Child Protection Unit
DDRC	District Disability Rehabilitation Centre
DDRS	Deendayal Disabled Rehabilitation Scheme
DEIC	District Early Intervention Centre
ECCE	Early Childhood Care and Education

GDP	Gross Domestic Product
GOI	Government of India
GDI	Gender Parity Index
ICDS	Integrated Child Development Services
ICT	Informations and Communications Technology
ISLRTC	Indian Sign Language Research & Training Centre
JJ Act	Juvenile Justice (Care and Protection of Children) Act, 2015
LLC	Local Level Committee
LMIC	Low and Middle-Income Countries
MHCA	Mental Health Care Act, 2017
MHRD	Ministry of Human Resource Development
MSJE	Ministry of Social Justice and Empowerment
MWCD	Ministry of Women and Child Development
NALSA	National Legal Services Authority
NALSAR	National Academy of Legal Studies and Research
NGO	Non-Government Organizations
NIEPID	National Institute for the Empowerment of Persons with Intellectual Disabilities
NIEPVD	National Institute for the Empowerment of Persons with Visual Disabilities
NILD	National Institute for Locomotor Disabilities
NILERD	National Institute of Labour Economics Research and Development
NIMHR	National Institute of Mental Health and Rehabilitation
OPD	Organization of Persons with Disabilities
ORDI	Organization for Rare Diseases India
PDUNIPPD	Pt. Deendayal Upadhyaya National Institute for Persons with Physical Disabilities
PA	Personal Assistant
POCSO	Protection of Children from Sexual Offences Act
PIL	Public Interest Litigation
RBSK	Rashtriya Bal Swasthya Karyakram
RCI	Rehabilitation Council of India Act, 1992
RINPAS	Ranchi Institute of Neuro-Psychiatry and Allied Sciences
RPwD Act	Rights of Persons with Disabilities Act, 2016
RTE Act	Rights of Children to Free and Compulsory Education Act, 2009
SAA	Specialized Adoption Agencies
SC	Scheduled Castes

SMC	School Management Committee
SIPDA	Scheme for Implementation of Rights of Persons with Disabilities Act
SLSA	State Legal Services Authorities
SMHA	State Mental Health Authority
SSA	Samagra Shiksha Abhiyan
ST	Scheduled Tribes
SVNIRTAR	Swami Vivekanand National Institute of the Rehabilitation Training and Research
TISS	Tata Institute of Social Sciences
UDID	Universal Disability Identity
UDISE	Unified District Information System for Education
WHO	World Health Organization

THE CONTEXT

Children with disabilities continue to be one of the most marginalized and invisible groups. Globally, it is estimated that 240 million or one in every 10 children have a disability. Majority of them are out of school, face high rates of malnourishment, and violence. They are 17 times more likely to be in institutions than their peers without disability and once inside, very unlikely to find exit pathways back to families and communities. While the Convention on the Rights of the Child (CRC) is applicable for all children including children with disabilities, somehow, they continued to be left behind. With the adoption of the Convention on the Rights of Persons with Disabilities (CRPD), a new era of inclusion for persons and children with disabilities began. Over the years, the jurisprudence emerging from the CRPD has led to paradigm shifts in how the rights of persons with disabilities need to be made real on the ground. Additionally, CRPD is well on its way to universal ratification. This means that more and more countries are now beginning to change their domestic laws and policies to align with the the Convention. India was one of the first few countries to have not only ratified the CRPD but also to have adapted its national legislations. The Rights of Persons with Disabilities (RPwD) Act 2016 and the Mental Health Care Act 2017 are laws that are aligned with the CRPD and currently cover the rights of persons and children with disabilities. The CRPD as well as the RPwD Act reinforce the right of children with disabilities to live with their families and in their communities, and their right to protection.

In 2024, the Children and Families Together – India (CAFT-India) program started to look at the larger care and protection landscape in India and how it is addressing the needs of children with disabilities. An assessment of existing scholarship revealed a concerning lack of data. The need for a rapid assessment emerged as a critical requirement. It was with this objective that CAFT-India undertook this study between June and September 2024 to understand the situation of care and protection for children with disabilities in India, with a focus on the state of Jharkhand.

While highlighting the areas where more work needs to be done, the report shines a light on the opportunities to bring greater convergence between the child protection and disability inclusion mechanisms. The rich data contained in this report also stands to inform ongoing discussions on inclusive care reform in both India and globally.

SECTION 1

Legislative and Policy Frameworks on Disability Inclusion: The Global Context

In the past few decades, there have been a gradual evolution in how our understanding of disability has evolved from charity to a medical model, to a social and human rights one. Children and persons with disabilities are no longer perceived as mere recipients of charity, but as rights holders with agency. The Convention on the Rights of Persons with Disabilities (CRPD) is the most significant milestone in this shift in understanding of disability. A human rights and social model of inclusion requires the recognition of all children as full members of society and the respect for all of their rights, regardless of age, gender, ethnicity, language, poverty or impairment. Inclusion involves the removal of barriers that might prevent the enjoyment of these rights and requires the creation of appropriate supportive and protective environments. The CRPD builds upon the existing provisions of other human rights frameworks including the Convention on the Rights of the Child (CRC) and opens a new era in securing the rights of children with disabilities and their families.[1]

The Convention on the Rights of Persons with Disabilities

There is a history of children and persons with disabilities being put away in institutions all over the world. This history comes from a world view where children and persons with disabilities are seen as very different from the 'normal' population; human beings who cannot take their own decisions, with little agency, who must be segregated from others in all aspects of their lives. Such a view focuses on the impairment of the child and sees that as a central defining feature of the child with little regard to their personhood. This practice of putting away and deprivation of liberty, often only based on disability, has also fuelled practices of violence and exploitation and abuse that are harmful to any child or person.

It is to counter this thinking and to reiterate that all children and persons with disabilities have human rights on an equal basis with others, that disability movements world over gathered strength in the late 1980s and 90s to advocate for an international law on the rights of persons with disabilities leading to the drafting and subsequent adoption of the Convention on the Rights of Persons with Disabilities (CRPD). The CRPD is historic in the way it was drafted in a participatory manner with persons with disabilities and organizations representing children with disabilities at the centre of negotiations together with Member States, unlike other such Conventions.

In October 2007, India became one of the first countries in the world to ratify the CRPD. With this, the nation entered into an international pact to bring in paradigm changes in the way disability rights are perceived as well as implementation of policy and program.

The paradigm shift of the CRPD starts with the understanding that disability is not just about the impairment or the medical condition of the child (or persons).

> ***It defines persons with disabilities as: "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."[2]***

"Respect *for difference and acceptance of disability as part of human diversity and humanity"*[3] is a powerful principle of the Convention. From this flows article 5 (equality and non-discrimination) which prohibits any discrimination 'on the basis of disability' and ensures the right of persons with disabilities, including children, to equal protection under the law. Equality in the context of disability does not mean treating all people in the same way and ignoring differences. Reasonable accommodations which are small, individualized changes needed by a child to have a level playing field with other children must be provided as a matter of right. **Any program designed for children with disabilities must provide for accommodations if they require them.**

Understanding the medical, human rights and social model of disability – As illustrated by Theresia Degener, former member of the Committee on the Rights of Persons with Disabilities[4]

The medical model of disability views disability as a deficit that needs to be treated, cured, fixed or at least rehabilitated. It is seen as a deviation from the normal health status. Exclusion of persons with disabilities from society is regarded as an individual problem, with the impairment that an individual has being the driver of exclusion. Disability according to the medical model remains the exclusive realm of helping and medical disciplines: doctors, nurses, special education teachers, rehabilitation experts. Another feature of the medical model of disability is that it is based on two assumptions that have a dangerous impact on human rights: Persons with disabilities need to have shelter and welfare, and impairment can foreclose legal capacity.

The first assumption legitimizes segregated facilities for persons with disabilities, such as special schools, living institutions or, sheltered workshops. The second assumption has led to the creation of mental health and guardianship laws that take an incapacity approach to disability

The social model of disability views disability as a social construct and locates the 'problem' of disability outside the individual in discrimination policies. The social model differentiates between impairment and disability. While the first relates to a condition of the body or the mind, the second is the result of the way the environment and society respond to that impairment.

Exclusion of persons with disabilities from society is politically analyzed as the result of barriers and discrimination.

The human rights model focuses on the inherent dignity of the human being. It places the individual at the centre in all decisions affecting them and locates the main 'problem' outside the person and in society. This model reinforces that human rights do not require absence of impairment and every individual is deemed to be of inestimable value and nobody is insignificant. People are valued not because they are economically or otherwise of value but because of their inherent self-worth. Human rights are fundamental rights. They cannot be gained or taken away from an individual or a group.

A group of rights overlay the General Principles of the Convention (article 3) creating the paradigm shift. Of these, the principle, "Respect *for difference and acceptance of persons with disabilities as part of human diversity and humanity*"[5] also underscores the powerful idea that children and persons with disabilities are not less than any other person but part of the great diversity of the human race. The right to live independently within the community with dignity and with adequate supports,[6] the right to choose where you live and who to live with, the right to found and be part of family[7] and the right to liberty[8] go clearly against the practice of institutionalization on the basis of disability.

This paradigm shift is reinforced by subsequent General Comments published by the Committee on the Rights of Persons with Disabilities (CRPD Committee), particularly the General Comment 5 on article 19 (living independently in the community) and General Comment 6 on article 5 (equality and non-discrimination).

However, to be able to live within communities, article 19 stresses that children and persons with disabilities must be able to *"access to a range of in-home, residential*[i] *and other community support services, including personal assistance necessary to support living and inclusion in the community".* Community services and facilities that are there for the general population, must be available to persons with disabilities and responsive to their needs.

Deepening this right, is the right to marry, to found a family and to stay within the family. Article 23 on home and family life, recognizes the right of the child to be part of their family. Acknowledging that children with disabilities are often ***concealed abandoned, neglected and segregated***, States must "*provide early and comprehensive information, services and support to children with disabilities and their families".*

Children should not be separated from their parents against their will, and on the basis of disability. Where the immediate family is unable to care for a child with a disability, every effort has to be made "to provide alternative care within the wider family, and failing that, within the community in a family setting".[9]

Recognizing the strong links between poverty and disability, and the additional disability related expenses that families have to bear, article 28 on adequate standard of living, calls for ensuring *"access by persons with disabilities, in particular women and girls with disabilities and older persons with disabilities, to social protection programs and poverty reduction programs."*[10] It advocates for access to food, clean water, clothing, housing, appropriate and affordable services, devices and other assistance for disability-related needs.

Persons with disabilities and their families living in situations of poverty must have assistance from the State with disability related expenses, including adequate training, counselling, financial assistance and respite care.[11]

Equal Recognition Before the Law

The agency of children and persons with disabilities in making choices about their lives is underlined in article 12 (equal recognition before the law).[12] The CRPD recognizes that persons with disabilities

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[i] The CRPD Committee's Guidelines on Deinstitutionalization including in the case of emergencies (CRPD/C/5, 2022) clarifies that "The reference to residential services in article 19 of the Convention should not be used to justify the maintenance of institutions. The term "residential services refer to community-based support services aimed at ensuring equality and non-discrimination in the exercise by persons with disabilities of their right to adequate housing." (pg 5, para 33)

may need support in taking decisions and asks that these supports are provided while maintaining the right of the person to equal recognition under the law. "Respect for inherent dignity, individual autonomy including the freedom to make one's choices and independence of persons" is a guiding principle of the Convention.

Many countries of the world, including India, have historically had laws that have prohibited persons with psychosocial and intellectual disabilities from taking decisions about their lives and guardianship regimes have continued even as the child becomes an adult. This has led to a lack of acknowledgement of agency of persons with disabilities and contributed to their institutionalization.

Equal recognition before the law and the capacity to make one's own decisions is one of the most contested provisions of the CRPD and it is also the most fundamental to the realization of all rights children and persons with disabilities. General Comment 1 of the CRPD Committee on article 12 reminds us that over the years many groups including women have been denied their right to equal recognition under the law.

The General Comment makes a distinction between the "legal recognition to hold rights and be recognized as a legal person before the law" and "the legal agency to act on those rights and have those actions recognized by the law" and asks that both strands be recognized and not separated. The second component to have "those actions recognized by the law" is frequently denied or diminished for persons with disabilities."[13,14] A person with a disability should have the right, for example, not only to own property but also to sell that property and decide what is to be done with the property.

Persons with disabilities may require support to take these decisions. The Convention therefore advocates for supported decision making wherever needed instead of substituted decision making.

Support can be formal such as a legally accepted support person or an obligation to make information available in accessible formats; or informal such as peer support and must be tailored according to the will and preference of the person. The great diversity of support and agency of children and persons with disabilities that is recognized in the Convention goes directly against the practice of institutionalization. It also has many lessons for those who actually run institutions for children and persons with disabilities. **The first is to not just "do what we consider to be the best interest of" the child but to ask for their views in all matters affecting their lives.**

"Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities", is one of the Principles of the Convention.[15] Contrary to commonly held views that some children with disabilities are so "*severely disabled*" that they will not develop or have the capacity to have their own views, the Principle and experience of the disability movement is that every child will develop at their own pace provided supports are given.

> ***It is not the child who has to fit into the system but rather the system must be flexible to include the child on an equal basis with others.***

A Focus on Inclusion

The inclusion of children and persons with disabilities in all mainstream systems, complemented by specific services and arrangements wherever needed is the underlying thrust of the CRPD. This ties in with the twin track approach to disability inclusion and is key to *"full and effective participation and* *inclusion"* which is one of the General Principles[16] of the Convention. The realization of the right to education in inclusive education systems,[17] access for children and persons with disabilities to health services, requiring "health professionals to provide care of the same quality to persons with disabilities as to others",[18] the right to work on an equal basis with others, to choose to work in a labour market, participate in political and public life on an equal basis with others, these are the thrusts of the rights outlined in the Convention. Age appropriate and gender specific protection services have to be provided to children and persons with disabilities who become victims of any form of violence exploitation and abuse (article 16).

Accessibility (Article 9)

Accessibility is the first requirement in the creation of a disability-inclusive world. Without ensuring accessibility, all other rights guaranteed to persons with disabilities become meaningless.[19] It is therefore not just a right in itself but also an enabler for all other rights enshrined in the Convention. As a General Principle and a separate article of the Convention, article 9 on accessibility widens conventional thinking and includes:

- Physical environment
- Transportation
- Information and communications, including Information and communications technologies and systems
- Facilities and services open or provided to the public, both in urban and in rural areas.

Diversity in Communication

Similarly, the Convention acknowledges the wide diversity in which children and persons with disabilities communicate. It widens both the definition of language by also including sign language and other forms of non-spoken languages.[20]

Communication includes:

> ***"Languages, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology."[21]***

Providing accessible information to children and persons with disabilities means having knowledge of all these different aspects of communication and providing information in the most appropriate format.

> ***For children, it also means that education and other systems such as the protection system must be geared to support children to learn ways of communication that are suitable to their abilities, and to communicate with them through their way of communication.***

Children with Disabilities

As a cross-disability Convention, the CRPD singles out a disability group in very rare instances. However, it highlights the vulnerability of children *(article 7),* women and girls with disabilities *(article 6*) through separate articles with the emphasis that all human rights apply to the child, women and girls with disabilities.

The agency of the child, the importance of hearing their views is stressed in the article. Children are to be provided with disability and age-appropriate assistance to realize that right.

Convention on the Rights of the Child (CRC) and Children with Disabilities

The CRC was the first human rights treat that included specific reference to disability under article 2 on non-discrimination and then a separate article 23 that was dedicated to children with disabilities. However, children with disabilities remained largely invisible in the implementation of the Convention. Taking cognizance of this, the Committee on the Rights of the Child came out with General Comment 9[22] on the rights of children with disabilities. The General Comment highlights the systemic barriers and exclusion faced by children with disabilities. It clarifies that the rights of children with disabilities should not be limited to the two articles that specifically refer to them, but it should be done in a comprehensive manner to cover all the articles of the Convention. The Committee goes on to reinforce that children with disabilities are best cared for and nurtured within their own family environment and that the family needs to supported to be able to care for the child. The Committee also highlighted the support needed by children of parents with disabilities and recommended that they should receive the support that would protect fully their rights and allow them to continue to live with their parents whenever it is in his or her best interests.

The Committee expressed its concern at the high number of children with disabilities placed in institutions and that institutionalization continues to be the preferred placement option in many countries. Furthermore, it raised concerns that children with disabilities are not often heard in separation and placement processes. It urged States parties to set up programs for deinstitutionalization of children with disabilities, placing them with their families, extended families or foster care system, with necessary and systematic supports required to care for the child in the home environment.

Clear Strategies for Implementation

The CRPD is not just an aspirational document. It lays down clear strategies for policy and program planning and implementation by drawing attention to the following:

- Addressing social economic, political barriers preventing the full participation of children and persons with disabilities, instead of focusing only on the medical condition. For example, there is a strong link between disability and poverty which determines their ability to access the required habilitation and rehabilitation services. There must be a strong web of social protection measures available to support inclusion in community programming and facilitate access to these services.
- Children with disabilities are children first and have all the needs and wants that children without disabilities have. They have their own personalities, likes, dislikes, need the same loving care as any other child, and need friends. Programs for children and for children with disabilities must address all these needs along with needs that are related to their impairment.
- Disability is an intersectional identity. Children with disabilities are part of all social and vulnerable groups in society. For example, Dalit children, tribal children, girls, working children, children belonging to different religions and castes in India. Strategies must consider these identities of the child as these can often lead to multiple layers of marginalization. Very often in our response to children, we continue to think of their impairment and not the person.

- Addressing strategies according to the different contexts in which children with disabilities live. For example, strategies for participation may differ in urban and rural areas. Children with disabilities living in tribal areas will be part of social mores of that society. It is important for programs to address their needs in relation to these different contexts and address the barriers accordingly.
- Children with disabilities have a right to be part of all sectors and services for child development in the country including education, health, development and child protection**.** Focus must be on the inclusion of all children in early childhood, health and education services.
- Inclusive strategies will require systems to change and be flexible to accommodate children with disabilities and move away from the one size fits all thinking.
- Settings for children with disabilities must recognize and support individuality and provide opportunities for **the exercise of choice and agency** in line with article 7 of the CRPD.

Guidelines for Deinstitutionalization including in Emergencies

The COVID-19 humanitarian crisis brought to the fore the dangers of institutionalization as many residents in closed door institutions died and were not prioritized during the humanitarian crisis.

> ***The pandemic "uncovered widespread institutionalization, highlighting the harmful impact of institutionalization on the rights and lives of persons with disabilities, and the violence, neglect, abuse, ill-treatment and torture, including chemical, mechanical and physical restraints, that they experience in institutions."***[23]

The Guidelines on Deinstitutionalization including in Emergencies published by the Committee on the Rights of Persons with Disabilities (CRPD Committee) after much consultation with persons with disabilities and their organizations, contend that the practice of institutionalization contravenes many of the articles of the CRPD. These include article 12 (a denial of legal capacity), article 14 (a deprivation of liberty based on disability). Further it "exposes persons with disabilities to forced medical intervention with psychotropic medications, such as sedatives, mood stabilizers, electro-convulsive treatment, and conversion therapy, infringing articles 15, 16 and 17".[24]

Most importantly it contravenes article 19 on the right to live in the community. The Guidelines ask that States parties *recognize institutionalization as a form of violence against persons with disabilities*. It further clarifies that States parties should abolish all forms of institutionalization, end new placements in institutions and refrain from investing in institutions. Institutionalization must never be considered a form of protection of persons with disabilities, or a "choice". The exercise of the rights under article 19 of the Convention cannot be suspended in situations of emergency, including in public health emergencies.

These Guidelines in fact go a step further from other guidance on deinstitutionalization and care reform by calling for States parties to "immediately halt new placements in institutions, adopt moratoriums on new admissions and on the construction of new institutions and wards, and refraining from refurbishing or renovating existing institutions.[25]

Defining Features of Institutionalization

Institutionalization of persons with disabilities refers to any detention based on disability alone or in conjunction with other grounds such as "care" or "treatment".

> ***Disability-specific detention typically occurs in institutions that include, but are not limited to, social care institutions, psychiatric institutions, long-stay hospitals, nursing homes, secure dementia wards, special boarding schools, rehabilitation centres other than community-based centres, half-way homes, group homes, family-type homes for children, sheltered or protected living homes, forensic psychiatric settings, transit homes, albinism hostels, leprosy colonies and other congregated settings. Mental health settings where a person can be deprived of their liberty for purposes such as observation, care or treatment and/or preventive detention are a form of institutionalization.***[26]

The CRPD Committee's Guidelines on Deinstitutionalization provide clear guidance on the defining characteristics of an institution. The Guidelines highlight the lack of choice and agency of the child and person with disability in such settings. These features include: [27]

- Obligatory sharing of assistants with others
- No or limited influence as to who provides the assistance
- Isolation and segregation from independent life in the community
- Lack of control over day-to-day decisions
- Lack of choice for the individuals concerned over with whom they live
- Rigidity of routine irrespective of personal will and preferences
- Identical activities in the same place for a group of individuals under a certain authority
- Supervision of living arrangements
- Disproportionate number of persons with disabilities in the same environment

Deinstitutionalization in the Context of Children with Disabilities

For children with disabilities, institutionalization can never be considered as a form of protection.[28] For children, the right to grow up in a family lie at the core of the right to be included in the community. An "institution", in the context of children, is any placement that is not family-based**.** All forms of institutionalization of children with disabilities – that is placement in any non-family setting, constitute a form of segregation, are harmful and violate the CRPD.

All institutions, including those run and controlled by non-state actors, should be included in deinstitutionalization reforms. The absence, reform or removal of one or more institutional elements cannot be used to characterize a setting as community based.[29] This is critical particularly for children with disabilities. Data shows that in India, children with disabilities constitute only five percent of the children in state-run Child Care Institutions (CCIs).[30] Given that children with disabilities are 17 times more likely than children without disabilities,[31] one assumption could be that many children with disabilities are in institutions run by non-state actors.

States parties must also offer all necessary supports to children with disabilities including financial support and include them in all aftercare policies and schemes that are available to care experienced youth without disabilities.

Steps to be taken for Deinstitutionalization

The Guidelines provide a range of actions that can be taken by States to ensure deinstitutionalization.

These include:

Community-based services[32]

- States parties should prioritize the development of a range of high-quality, individualized support and inclusive mainstream services in the community, without delay.
- Support services include personal assistance, peer support, supportive caregivers for children in family settings, crisis support, support for communication, support for mobility, the provision of assistive technology, support in securing housing and household help, and other community-based services.
- Support should also be available to gain access to and use mainstream services in areas such as education, employment, the justice system and health.

Allocation of Resources[33]

- Investments in institutions, including renovation, should be prohibited. Investments should be directed towards the immediate release of residents and the provision of all necessary and appropriate support for living independently.
- Accessible housing and the participation of persons with disabilities is advocated.
- States parties should provide persons with disabilities, including children with disabilities, leaving institutions with a comprehensive compensatory package comprising goods for daily living, cash, food vouchers, communication devices and information about services available, immediately upon departure. Such packages should provide basic security, support and confidence to persons with disabilities leaving institutions, in order that they can recover, seek support when they require it, and have an adequate standard of living in the community without risk of homelessness or poverty.

Deinstitutionalization to be Grounded in Dignity[34]

- Deinstitutionalization processes should be aimed at restoring dignity and recognizing the diversity of persons with disabilities. Assessment of capacities for independent living based on impairment is discriminatory and should shift to assessment of individualized requirements and barriers to independent living in the community.
- For many, the institution may be the only living environment that they know. States parties should be held accountable for limiting the personal development of institutionalized people and should not create new barriers to leaving institutions by attributing “vulnerability” or “weakness” to persons with disabilities.
- States parties should provide multiple options for those leaving institutions and ensure access for persons with disabilities to the support that they may require in decision-making.

Deinstitutionalization Must be Led by Persons with Disabilities[35]

- Processes of deinstitutionalization should be led by persons with disabilities, including those affected by institutionalization, and not by those involved in managing or perpetuating institutions.
- States parties should closely involve persons with disabilities, and their representative organizations (Organizations of Persons with Disabilities or OPDs), and give priority to the views of persons leaving institutions and survivors of institutionalization, and their representative organizations, in all stages of deinstitutionalization processes.
- States parties should establish open and inclusive planning processes, ensuring that the public understands article 19 of the CRPD, the harms of institutionalization and exclusion of persons with disabilities from society, and the need for reform.

Women and Girls with Disabilities

The Guidelines acknowledge that women and girls with disabilities are at a heightened risk of violence, exploitation and abuse compared to women and girls without disabilities. These include practices such as forced contraception, forced abortion and sterilization, during institutionalization. They are denied the right to exercise their legal capacity, leading to lack of access to justice, choice and autonomy. These risks should be considered when designing and implementing deinstitutionalization plans.

Actions to be Taken for Children with Disabilities[36]

- Deinstitutionalization should be directed in line with children's right to family life, in accordance with their best interests. States parties should ensure the right to family life for all children with disabilities.
- Support for children with disabilities and families, as early as possible, should be included in mainstream support for all children. Peer support for children and adolescents is essential for full community inclusion.
- Opportunities for family-based placements, with financial and other forms of support, should be created for all children with disabilities. Placement with the family of origin should be considered before any alternative family arrangements are made.
- States parties should provide parents with disabilities with support and reasonable accommodation to prevent their children from being placed in institutions and should put in place inclusive child-protection systems.
- Support and reasonable accommodation should be provided to ensure that children and adolescents with disabilities can express their will and preferences and be involved in matters of personal choice and in public policymaking.
- States parties should develop and ensure access to support services in the community, including personal assistance and peer support, for children and adolescents with disabilities.
- Education systems should be inclusive. States parties should include children with disabilities in mainstream schools, and prevent placement in segregated education, which undermines community inclusion and leads to increased pressure to place children in institutional settings.

- To prevent the institutionalization of children, accessible information should be made available to families and children. It should be presented in multiple user-friendly formats through schools, community centres, doctors' offices, health-care facilities, parents' resource centres and religious institutions.
- Training of professionals, including child-protection professionals, on the human rights model of disability is key to preventing situations in which families are advised or encouraged to place their child in an institution.

Core Element of Article 19 of the CRPD

The Guidelines on Deinstitutionalization must be read together with the article 19 of the CRPD on living Independently and in the community. Both are simultaneous processes and any focus on deinstitutionalization without creating supports in the community are bound to fail. Persons with disabilities have historically been denied their personal and individual choice and control across all areas of their lives. Many have been presumed to be unable to live independently in their self-chosen communities. Support is either unavailable or tied to particular living arrangements, and community infrastructure is not universally designed. Resources are invested in institutions instead of developing possibilities for persons with disabilities to live independently in the community. This has led to abandonment, dependence on family, institutionalization, isolation and segregation.[37]

General Comment 5 of the CRPD Committee on article 19 clarifies that living independently "does not necessarily mean living alone" nor should it be interpreted "solely as the ability to carry out daily activities by oneself". Rather, it should be regarded as the freedom to choose and control, in line with the respect for inherent dignity and individual autonomy as enshrined in article 3 (a) of the Convention. Independence as a form of personal autonomy means that the person with disability is not deprived of the opportunity of choice and control regarding personal lifestyle and daily activities.[38]

Article 19 requires that there be individualized supports for children and persons with disabilities along with accessibility and inclusion in all the mainstream services available for all persons in the community. These supports must be such that they are chosen and guided by the person, once again emphasizing the elements of choice and agency of children and persons with disabilities. The aim of these support services must be the inclusion of persons with disabilities and not isolation. Support services must be available, accessible, affordable, acceptable and adaptable to all persons with disabilities and be sensitive to different living conditions and individual circumstances.

The provision of assistive devices, mobility aids, easy to understand information, accessible housing and easy access to justice, are just some pre-conditions of being able to live independently in the community. Equally important is the recognition of disability related costs and links between poverty and disability and affirmative action to this end in policy and program.

The General Comment also clarifies that article 19 applies to all persons with disabilities including persons with disabilities who are assessed as requiring a high level of personal service, such as "persons with intellectual disabilities, especially those with complex communication requirements, among others, who are often assessed as being unable to live outside institutional settings".[39] Reasoning of States that it is too expensive to provide this support or that this is best provided in an institution is contrary to article 19, "which extends the right to live independently and be included in the community to all persons with disabilities, regardless of their level of intellectual capacity, self-functioning or support requirements."[40]

SECTION 2

The Indian Context: Legal and Policy Provisions for the Rights of Children with Disabilities in India

In 2007 when India ratified the CRPD, there were already four disability laws in the country.

1. The Persons with Disabilities Equal Opportunities, Protection of Rights and Full Participation Act 1995
2. The Mental Health Act 1987
3. The National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act 1999
4. The Rehabilitation Council of India Act 1992

In 2016, the Persons with Disabilities Act of 1995 was repealed and replaced by the Rights of Persons with Disabilities Act (RPwD Act) 2016. The Mental Health Act of 1987 was repealed and replaced by the Mental Health Care Act (MHCA) of 2017. The other two laws are yet to be aligned with the CRPD and have not been amended.

The Rights of Persons with Disabilities Act 2016

Similar to the negotiations of the CRPD, the drafting process of the RPwD Act 2016 also had persons with disabilities and their organizations at the forefront of all discussions and decisions. Several cross-disability meetings strengthened the collective advocacy with different impairment groups coming together and finding common cause with each other in the drafting of a new law. In keeping with the principle of 'Nothing About Us Without Us', the drafting committee of the law had persons with disabilities as well as representatives of Organizations of Persons with Disabilities (OPDs). Starting in 2010, the process of discussion and debate ended in December of 2016 with the Indian parliament adopting the RPwD Act.

The RPwD Act echoes the CRPD across many of its chapters and aims to bring the paradigm shift that the Convention envisioned.

New Terms and Concepts

Like the CRPD, the RPwD Act 2016, initiates a paradigm shift in disability rights in the country. The definition of persons with disabilities,[41] is the same as in the CRPD. However, the law specifies that only persons with 'benchmark disabilities'[42] can get a disability certificate and avail all the schemes and programs for children and persons with disabilities. For example, in Chapter VI sections 31 to 34 of the law talk about free education for persons with benchmark disabilities, reservation in higher education as well as reservation in government jobs. For children, it means that only students with benchmark disabilities would be entitled to get free books, other learning materials and appropriate assistive devices as well as scholarships.

Some new terms[43] introduced in the RPwD Act 2016 include:

Benchmark Disabilities: The law defines a person with benchmark disability as someone who has not less than 40 percent of a specified disability (disabilities specified in the Schedule of the law).

High Support Needs: The RPwD Act discards the earlier labels of 'mild,' moderate,' 'severe' and 'profound', terms that were based on very medical understanding of disability and brings in the understanding that some persons with disabilities will need high support in their lives. Chapter VII on special provisions for high support needs details that the State must provide support to children and persons with high support needs once they are assessed by a board.

Caregiver: The RPwD Act recognizes the importance of the caregiver and talks about caregiver allowance to persons with high support needs.

Reasonable accommodation refers to necessary and appropriate modification and adjustments not imposing a disproportionate burden, that are customized to individual needs, and which allow the person with a disability to enjoy or exercise all human rights and fundamental freedoms on an equal basis with others of.

Other important terms and concepts include the concept of 'reasonable accommodation', a wider definition and recognition of 'communication' and 'accessibility' as in the CRPD as well as a first-time definition of 'inclusive education.'

RPwD Act and Children with Disabilities

As in the CRPD, children with disabilities find special mention in the RPwD Act as well. Section 4 of the law is on women and children with disabilities and states that:

"The appropriate government and the local authorities shall take measures to ensure that the women and children with disabilities enjoy their rights equally with others.

The appropriate government and local authorities shall ensure that all children with disabilities shall have right on an equal basis to freely express their views on all matters affecting them and provide them appropriate support keeping in view their age and disability."[44]

A Wider Range of Rights

While the Persons with Disabilities Act 1995 was limited largely to education, employment, prevention and early detection of disabilities and non-discrimination in specific areas, the RPwD Act 2016 references a wider range of rights and recognises twenty-one (21) impairment groups as opposed to the 7 groups recognised in the 1995 law.

Care and Protection

A range of rights support children with disabilities to live in the community and be included in services for all children in the community. The right to inclusive education, access to free healthcare, priority in attendance and treatment, barrier free access in all healthcare institutions[45] are rights that can support children and persons with disabilities to continue to live within their own communities. The right to cultural activities[46] and right to sports activities[47] an acknowledgement of the areas where children and persons with disabilities tend to get excluded.

The law is very clearly against institutionalization when it details the right of children and persons with disabilities to live in the community with 'support services, including personal assistance to support independent living'.[48] Children with disabilities have a right not to be separated from their families unless absolutely necessary.

> ***Section 9(2) puts clear checks and balances when it says, "Where the parents are unable to take care of a child with disability, the competent court shall place such child with his or her near relations, and failing that within the community in a family setting or in exceptional cases in shelter home run by the appropriate Government or non-governmental organization, as may be required".***[49]

Violence, exploitation, abuse and torture take on a different colour when it comes to children and persons with disabilities. In the garb of care and protection, many actions that are condemned for other children are often condoned as part of the rehabilitation process for children with disabilities. For example, the use of restraints for long periods of time, forced hysterectomies of girls with disabilities, the use of psychotropic medication without consent are just some of these actions. The extreme isolation of some children from the world and lack of peer support is nothing short of violence and neglect of the child by society in general.

Recognizing this, the RPwD Act 2016 has an extensive section on protection from violence abuse and exploitation.[50] While the law talks about prevention of such situations, it also empowers the Executive Magistrate to take steps to rescue, protect and rehabilitate victims of such incidents. Any organization or individual can report to the Magistrate any wrongdoing against a child or person with a disability.

Equal protection and safety are also enshrined during situations of risk, armed conflict, humanitarian emergencies and natural disasters[51] and with clearly defined roles for disaster management authorities in the law.

Access to Justice

Children and persons with disabilities face many barriers in accessing justice. The inaccessibility of justice systems has recently been brought out in a report submitted to the Supreme Court.

A survey of High Courts found that while some accommodations exist for persons with locomotor disabilities, there is limited awareness of needs for other disabilities. District courts, especially in rural areas, face significant accessibility challenges.[52] This has been pointed out earlier in a compilation of a series of studies on the implementation of the POCSO (Protection of Children from Sexual Offences) Act) in different states (Andhra Pradesh, Assam, Delhi, Karnataka, and Maharashtra).[53] The report point out the lack of physically accessible courts including accessible toilets,[54] the lack of mental health professionals and training amongst personnel in the justice system of the country.

The RPwD Act gives clear instructions on how access to justice should be made easier for children and persons with disabilities.

> ***"The appropriate Government shall take steps to put in place suitable support measures for persons with disabilities specially those living outside family and those disabled requiring high support for exercising legal rights."***[55]

The National Legal Services Authority (NALSA) and the State Legal Services Authorities (SLSA) are charged with making "provisions including reasonable accommodation to ensure that persons with disabilities have access to any scheme, program, facility or service offered by them equally with others."

Another major ask that is important for children with disabilities coming into contact with the justice system is to "make available all necessary facilities and equipment to facilitate recording of testimonies, arguments or opinion given by persons with disabilities in their preferred language and means of communication."

Office of the Chief and State Commissioners

The Office of the Disability Commissioner instituted since the earlier 1995 law continues to be the major office where children and persons with disabilities can approach with a grievance. The role of the Commissioners both at the state and the national level is to address grievances, monitor the implementation of the law and its schemes and take *suo moto* cognizance of deprivation of rights,[56] among others.

The National Trust Act 1999

The National Trust Act for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities, 1999 was formulated as an acknowledgment of the big questions that families of persons with these disabilities faced: ***What will happen after me?***

In the absence of support systems, parents were worried about who would look after their child after they were no longer able to do so. Important decisions of money, care services, property decisions, etc. were largely issues that persons with high support needs require support with. It is important to note that this law predates the CRPD and was a reaction to the realities of that time, primarily the lack of recognition of legal capacity of persons with disabilities and other issues that the erstwhile Persons with Disabilities Act 1995 did not address. In such a scenario, families would get guardianship of their family member with a disability under the Guardian and Wards Act. However, this was a long and tedious process, and many families raised these questions. The National Trust Act was drafted as an answer to this question and an acknowledgement that some children and persons with disabilities were vulnerable in the areas of decision making.

The objectives of the Trust include:

- To enable and empower persons with disabilities to live as independently and as fully as possible within and as close to the community to which they belong.
- To strengthen facilities to provide support to persons with disabilities to live within their own families; to extend support to registered organizations to provide need-based services during period of crisis in the family.

- To deal with problems of persons with disabilities who do not have family support; to promote measures for the care and protection of persons with disabilities in the event of death of their parents or guardians.
- To evolve procedure for the appointment of guardians and trustees for persons with disabilities requiring such protection.

Guardianship

In a big shift from accepted practice, the National Trust Act took the legal act of guardianship from the courts to a Local Level Committee (LLC) consisting of a person with disability, the District Magistrate and a member of a non-government organization. The LLC is formed at the district level in every state of the country.

The law was ahead of its times on the issue of guardianship as it did try and differentiate between guardianship of the person and guardianship of property. **However, with India ratifying the CRPD this needs to be reviewed and changed**.

The Mental Health Care Act 2017

The Mental Health Care Act (MHCA) 2017 repealed the earlier Mental Health Act, 1987 and brought in some significant changes into how mental health is treated. According to the law, determination or diagnosis of mental illness can be done only in accordance with nationally and internationally accepted medical standards.[57,58] It does not equate mental illness with incapacity as was done earlier. A person can have a mental illness and still have capacity to make decisions regarding one's own health care and treatment. The law brought in progressive instruments such as Advanced Directives and Nominated Representative to fall back on if they were ever in a position where they were unable to take their own decisions.

Persons with mental illness have a right among others, to equality and non-discrimination, right to Information regarding details of their admission, mental illness, treatment plan and a right to live in and be a part of society. They cannot be segregated or excluded from their community.

The law gives detailed instructions on the different ways in which a person with mental illness can be admitted to a mental health facility and emphasizes the importance of informed consent.

The law brought in the Central and State Mental Health Authority (CMHA and SMHA) as regulatory bodies set up under the central and state governments respectively for implementing the MHCA, laying down minimum standards for mental health care services, registration of mental health establishments and registering mental health professionals.

Mental Health Review Boards are official bodies which have powers to conduct proceedings to protect the rights of persons with mental illness and ensure proper implementation of the provisions of the MHCA. They are chaired by a District Judge and members include a representative of the District Collector, one psychiatrist, one medical practitioner and two representatives of persons with mental illness or caregivers or NGOs working in the field of mental health. These boards can take decisions regarding review of advance directives, appointment of Nominated Representatives, and address complaints against deficiency of services and violations of rights.

The Rehabilitation Council of India Act 1992

The Rehabilitation Council of India (RCI) Act 1992 was brought in to regulate the training of personnel who work in the field of rehabilitation. Without RCI certification, professionals are not allowed to work with children and persons with disabilities. However, this law has still not been aligned with the CRPD, which presents a great challenge in creating a workforce that aligns to values of inclusion. In the area of education for example, the RCI continues to train teachers in teaching children with singular disabilities while the RPwD Act focuses on inclusive education. Since children and persons with disabilities are to be a part of every area of development, there is a great need today to have courses that can be taken by a range of professionals in different areas, for example in child protection.

SECTION 3
Disability Specific Programming

Disability is a state subject which means that disability focused programming in India is led by the state governments. Disability comes under the domain of the Ministry of Social Justice and Empowerment (MSJE). While issues related to children comes under the Ministry of Women and Child Development (MWCD), those of children with disabilities have historically continued to be primarily under MSJE. This has unfortunately led to the rights of children with disabilities being looked at as separate from those of children without disabilities, reinforcing the charity and medical approach to disability.

In 2012, the Department of Empowerment of Persons with Disabilities (DoEPwD), now Department of Empowerment of Persons with Disabilities, Divyangjan, was created within the MSJE. The aim was to have greater focus on policy matters to effectively address disability issues and to act as a nodal department for greater coordination among other ministries, departments, and state governments.[59] It was this department that worked actively with disability groups to draft the new laws, the Rights of Persons with Disabilities Act 2016, and the Mental Health Care Act 2017. The Department also runs several disability specific schemes and programs. While there are none that directly focuses on care and protection, there are schemes that are part of creating safety nets for children with disabilities. The MSJE also has institutions under its jurisdiction that provide a range of services.

National Institutes are autonomous bodies set up under the Department of Empowerment of Persons with Disabilities. These institutes are primarily engaged in human resources development in the field of disability and conduct various courses, provide rehabilitation services to persons with disabilities and promote research and development efforts in the particular field of disability. There are 10 National Institutes listed under the Department:[60]

- National Institute for the Empowerment of Persons with Visual Disabilities (NIEPVD), Dehradun
- Ali Yavar Jung National Institute of Speech and Hearing Disabilities (AYJNISHD)
- National Institute for the Empowerment of Persons with Intellectual Disabilities (NIEPID)
- National Institute for Empowerment of Persons with Multiple Disabilities (NIEPMD)
- Pt. Deendayal Upadhyaya National Institute for Persons with Physical Disabilities (PDUNIPPD)
- Swami Vivekanand National Institute of the Rehabilitation Training and Research (SVNIRTAR)
- National Institute for Locomotor Disabilities (NILD)
- Indian Sign Language Research & Training Centre (ISLRTC)
- National Institute of Mental Health and Rehabilitation (NIMHR)
- Atal Bihari Vajpayee Training Centre for Disability Sports – Gwalior

Additionally, there are 25 Composite Regional Centres (CRCs) that act as extended arms of National Institutes. They provide rehabilitation services to persons with disabilities, train rehabilitation professionals, workers and functionaries, undertake education and skill development programs and create awareness among parents and the community regarding needs and rights of persons with disabilities.

Child Budgeting in India

In 2008-09, government of India started publishing a separate statement (Statement 22, which is now Statement 12) within the Expenditure Budget - Volume I, which summarizes the Budget Provisions for Schemes for the Welfare of Children across all sectors that substantially benefit children.

The 2013 National Policy for Children also explicitly highlights the importance of child budgeting exercise by stating that it is important to 'track allocation and utilization of resources and their impact on outcomes for children with regard to budgets and expenditures on children by all related ministries and departments'.

This has given both governments and civil society a tool to examine the progress we are making in our commitments to children. Given disability is a state subject, states often have their own schemes for children or persons with disabilities in addition to the central government schemes.

Budgets from a CRPD Lens

The CRPD focuses on the inclusion of children with disabilities in all areas of development and therefore has implications for budgets. To adhere to the principles of the CRPD, budgets must follow a twin track approach – all allocation such as those for education, health, protection, child development must include a component on disability, while also providing specific schemes for persons with disabilities. While analyzing budgets from a CRPD lens, it is also important to assess whether the allocations are in line with the underlying paradigm shift in our understanding of disability. For example, the CRPD provision of right to family will not be realized if the quantum of money spent on institutions is consistently higher than community-based approaches, or on strengthening the family.

The Extra Costs of Disability

Adequate Standard of Living and Social Protection

Article 28 of the CRPD recognizes that children and persons with disabilities will have disability related expenses. These expenses, for example, may include money spent on assistive devices for children with disability. Some children with disability will require personal assistance to move or complete daily activities.

Invisible Expenses

This is another aspect that needs to be considered when budgeting for children with disabilities. For example, a parent of a child with a disability foregoing income generating or livelihood activities due to caregiving responsibilities and lack of support services is an invisible cost. Given the gender bias in society, it may just be assumed that it is the mother who has to stay back home. Expenses that are invisible also include those incurred from multiple hospital visits when parents are struggling to understand their child's impairment to getting a disability certificate. Parents may have to take a more expensive form of transport because of the inaccessibility of the public transport system.

Families of children with disabilities may migrate to larger urban centres in the hope that their child will get better services. This move will entail many extra costs, both economic and emotional, for the family.

> ***It has been calculated that families with children and persons with disabilities "require at least 40 percent of average income to have same standard of living as a household without persons with disabilities."***[61]

RPwD Act and Budgets

Section 24 of the Rights of Persons with Disabilities Act 2016 on social security mandates the government to formulate schemes and programs to safeguard and promote the rights of persons with disabilities for adequate standard of living to enable them to live independently or in the community. It also states that the quantum of assistance to persons with disabilities under such schemes and programs shall be **at least twenty-five per cent higher than the similar schemes applicable to others.[62] Free education for children with benchmark disabilities[63] and free healthcare are other clearly budget related promises of the 2016 law.**

The social protection measures enshrined within the RPwD Act is aimed at providing support for community inclusion for persons with disabilities with the caveat of an income ceiling. It covers among others:

- Provisions of aids and appliances, medicine and diagnostic services and corrective surgery free of cost to persons with disabilities
    - Disability pension
    - Unemployment allowance
    - Caregiver allowance for persons with disabilities with high support needs and
    - Comprehensive insurance scheme[64]

There is also the provision of a National Fund in the RPwD Act[65] that supports exhibitions, workshops to showcase products made by persons with disabilities, and persons with benchmark disabilities excelling in sports or the arts to participate in national and international events.[66]

Disability in Union Budgets

In India, the concept of analyzing annual Union Budgets from a CRPD lens is a relatively new concept that started roughly a decade back. Data in recent years suggests a decreasing trend in allocation. In 2019-2020, the allocation for disability in the Union Budget as a percentage of GDP was 0.010 percent which reduced to 0.008 in 2023-2024.[67]

A look at allocations and expenditures of the Department of Empowerment of Persons with Disabilities (DoEPwD) under the Ministry of Social Justice and Empowerment shows an increase in allocations, which is a positive sign. Higher allocation will go a long way in ensuring that the mandate of the RPwD Act is translated into tangible schemes and services, even though actual expenditures have been lower than allocation.[68]

Budget Allocation and Expenditure

Year	Budget Estimated	Revised Estimated	Actual Expenditure (Rupees in crores)
2018-19	1070.00	1070.00	1017.56
2019-20	1204.90	1100.00	1016.18
2020-21	1325.39	900.00	861.63
2021-22	1171.77	1044.31	1009.45
2022-23	1212.42	1015.98	571.51 (As on 31.12.2022)

Source: The Department of Empowerment of Persons with Disabilities, GOI, Annual Report 2022-23.[69]

Programs and Schemes for Children with Disabilities

When it comes to programs and schemes for children with disabilities on the ground, there is a mix of new schemes as well as those that have continued from the 1990s. While there is no scheme that expressly focuses on prevention of institutionalization, a few schemes and programs continue to promote it. However, programs that support education, early intervention, and provision of assistive devices can be counted as creating a social protection web around the child that enables them to live with their families and in the community, reducing their risk of institutionalization.

District Disability Rehabilitation Centres (DDRCs)

These rehabilitation centres have a mandate to provide rehabilitation support through early intervention, assessments and provisions of assistive devices, therapeutic services, assistance in scholarships, survey and identification of persons with disabilities through camp approach, facilitation of disability certificates, assisting in the issue of accessing Universal Disability Identity (UDID) cards, among others.

Since its inception in 1990, the plan has been to have District Disability Rehabilitation Centres in all the districts of India. However, in 2021-22 only 269 such rehabilitation centres have been set up with the "number of DDRCs functioning and getting regular grant being 55-60"[70]. Although some of these DDRCs have recently been upgraded,[71] their numbers seem to be dropping across the years with 45 DDRCs assisted in 2018, 22 in 2019, 28 in 2020-21 and 11 till 31/12/2022.[72] It should be noted that at the time of their inception, it was planned that the DDRCs will be handed over to district administration after a period of 3 years, but states were not inclined to take over on account of the budget implications. The funding of the Scheme was shifted under the Scheme for Implementation of Provisions of Persons with Disabilities Act (SIPDA).[73]

Even though the district is a very large geographic unit, having a DDRC can assist in convergence with different initiatives and systems of health education and protection. Some states are opening new DDRCs with Hazaribagh in Jharkhand getting one such service centre in 2022-23.

Although children with disabilities would be accessing these centres, there is no segregated data on the numbers of children with disabilities accessing DDRCs.

DDRCs assisted, amount released during 2018-19 to 2022-23[74]

Year	Jharkhand		National	
	Amount (in Rupees)	No. of DDRC	Amount (in Rupees)	No. of DDRC
2018-19	-		5,26,45,456	45
2019-20	-		3,17,59,962	22
2020-20	-		5,75,56,397	28
2021-22			5,56,71,768	24
2022-23 (as on 31-12-2022)	26,09,250	1	1,21,91,928	9

Source: The Department of Empowerment of Persons with Disabilities, GOI, Annual Report 2022-23.

Deendayal Disabled Rehabilitation Scheme

The Deendayal Disabled Rehabilitation Scheme (DDRS) scheme provides support to non-government organizations (NGOs) for model projects such as Pre-School and Early Intervention and Training (for children up to 6 years of age), special schools for children with hearing impairment and vision impairment including a home based and community-based rehabilitation (CBR) component. Under this scheme, special schools can also include residential facilities.[75]

The other projects under the scheme include project for rehabilitation of leprosy cured persons, halfway homes for psychosocial rehabilitation of "treated and controlled mentally ill persons".[76]

CBR projects are merged with the existing model projects and tend to be centre and school based, the reach of these projects is small and uneven across the country. The number of "beneficiaries" countrywide from 2018 to 2021-22 were between 30,000 and 40,000 per year.

Number of proposals received, number of proposals sanctioned, fund released and beneficiaries during 2018-19 to 2022-23 under DDRS[76]

Year	Proposal Received	Sanctioned	Fund Released (Rupees in lakhs)	Beneficiaries	NGO	Grant-in-Aid released to NGO (Rupees in lakhs)
2018-19	524	543	6999.90	41803	NA	NA
2019-20	460	432	10166.84	38004	NA	NA
2020-21	405	340	7742.49	31542	189	491,2.45
2021-22	416	318	9532.78	30082	185	3,934.76
2022-23 (as on 31-12-2022)	28	214	4895.32	17897	214	4,895.32

Source: The Department of Empowerment of Persons with Disabilities, GOI, Annual Report 2022-23.

Assistance to Disabled Persons for Purchase/Fitting of Aids/Appliances (ADIP)

This scheme is for the provision of assistive devices to children and persons with disabilities and operates through the camp approach. A list of the assistive devices available to children and persons with disabilities is available on the website of the Department of Empowerment of Persons with Disabilities.

One of the most popular and well-funded schemes, the ADIP scheme also has a tie-up with the Samagra Shiksha Abhiyan (SSA) for school going children. This is an excellent example of convergence where two ministries work together to provide assistive devices to children.

An evaluation conducted by the National Institute of Labour Economics Research and Development (NILERD) revealed that 86 percent of the beneficiaries were between 15 and 59 years of age. Out of this, 48.53 percent got employment after fitting of aids and appliances. Thirty-nine percent "beneficiaries" started studying after receiving the aids/appliances, 51.98 percent resumed work after fitting, 66.10 percent experienced improvement in mobility, and 52 percent reported improvement in caretakers' lives. Further, 30.57 percent reported reduced dependency on others."[78]

ADIP Scheme and Children with Disabilities

Children require training and follow-up to use an assistive device. For example, when a child is given a hearing aid in the camp, the parents or caregivers need to understand how to use the aid, how to keep it clean, when and if batteries have to be changed. The child is unlikely to accept the aid immediately and will require persistence and training to use it.

Parents and families need to know where to go in case there is damage to the assistive device. These facilities need to be available near the place where the child lives.

As of now, the scheme does not include the possibility of incorporating reasonable accommodations for individuals. For example, if a child requires a modification in their wheelchair to suit their needs, it would not be available through the scheme.

The importance of this scheme cannot be over emphasized. It is therefore essential to expand its reach. In the last 3 years, between 200,000-400,000 persons with disabilities have been supported with assistive devices. However, there is no disaggregation available by age of gender to understand how the scheme has impacted the lives of children with disabilities.

Details of camps conducted, funds utilized, and number of beneficiaries covered under various activities during the last three years and current year (up to 31.12.2022) by various Implementing Agencies under ADIP Scheme[79]

National			
Year	**No. of Camps**	**Funds utilized (Rupees in lakh)**	**No. of Beneficiaries**
2018-19	1,134	20,243	3,00,865
2019-20	1,156	20,572	3,51,629
2020-21	1,356	17,880	2,58,749
2021-22	1,762	19,532	2,43,387
2022-23 (as on Dec 22)	736	14,527	1,40,266

Source: Department of Empowerment of Persons with Disabilities, GOI, Annual Report 2021–22.

While the 2024-25 budget shows an increase in the allocation to this scheme, from 245 crores estimated budget in 2023-24 to 315 crores in 2024-25, there is a recommendation for an increase in allocation to upscale the scheme to include assistive devices listed in the World Health Organization (WHO) recommended Priority List for Assistive Devices for children and persons with disabilities.[80]

Scheme for Implementation of the Rights of Persons with Disabilities Act 2016 (SIPDA)

SIPDA is a large umbrella scheme which has many components that are supposed to aid the implementation of the RPwD Act 2016. This scheme was revised in 2021 and now includes ten sub schemes such as the Accessible India Campaign, which is the flagship program of the Ministry of Social Justice and Empowerment, the DDRCs, the Composite Resource Centres (CRCs), and new cross disability early intervention centres started by the government.

The budget allocation and expenditure under this scheme is placed in the table below.

Budget Allocation and expenditure SIPDA during 2017-18 to 2022-23[81]

Year	BE Allocation (Rupees in crores)	RE Allocation (Rupees in crores)	Amount released (Rupees in crores)
2017-18	207.00	273.06	272.24
2018-19	300.00	258.30	260.82
2019-20	315.00	260.00	217.34
2020-21	251.00	122.89	103.43
2021-22	209.77	147.31	108.44
2022-23	240.39	-	21.40

Source: Department of Empowerment of Persons with Disabilities, GOI, Annual Report 2022–23.

Accessible India Campaign

The Accessible India Campaign is a flagship program of the Ministry of Social justice and Empowerment for achieving universal accessibility. The campaign includes accessibility audits and making public places and infrastructure fully accessible in the built environment, transportation and ICT eco-system. However, the budget allocations for this particular scheme indicates a downward trend with 66.34 lakh rupees in 2020-21 to 61.14 lakh rupees in 2021-22 to 41.15 lakh rupees in 2022-23.[82]

Right to Accessibility

The RPwD Act 2016 ensures the right to accessibility through its sections 44 through 46 that makes compliance with accessibility norms mandatory. Section 44 lays down the consequences of noncompliance, Section 45 requires retrofitting to be undertaken in accordance with “the rules on accessibility formulated by the central government” and section 46 requires service providers to make their services accessible within a period of two years from the notification of the rules for the implementation of the law. Rules for accessibility have been included in Chapter VI of the Rights of Persons with Disabilities Rules. The mandatory accent has been retained in the chapeau of Rule 15, which states that “every establishment shall comply with the following standards relating to environment, transport, and information technology.”

However, these standards which must be complied with have been incorporated in documents which are described as Guidelines.' These guidelines provide choice in implementation and do not enforce compliance. This led to a dilution of the right of accessibility in the law.[83]

In a landmark judgement by the Supreme Court of India in the matter of Rajive Raturi vs Union of India[84], WP (Civil) 243/2005 ruled that Rule 15 (1) is ultra vires of the legislative intent of the RPwD Act. It further went on to say that "Creating a minimum floor of accessibility cannot be left to the altar of "progressive realization". It has now asked the Union Government to delineate mandatory rules as required under section 40 within a period of three months from the date of judgement.

State-Wise Variation in Programs

A review of budget allocations across different states indicates significant variations, including in the number of people reached. For example, in 2021-22, the number of proposals sanctioned under the DDRS scheme was 49 for Andhra Pradesh, 39 for Odisha, 43 for Uttar Pradesh, 40 for Telangana and none for Jammu and Kashmir, Jharkhand and Arunachal Pradesh.[85] In terms of numbers of beneficiaries, Odisha reported 5306 in 2021-22, Maharashtra 1677, Kerala 1883, and Rajasthan 582. Jammu and Kashmir, Tripura and Jharkhand had no beneficiaries. The lack of segregation of data by gender and by age does not allow for further analysis and planning for children.

Similarly, the number of beneficiaries of the ADIP scheme for a three-year period ending in December of 2022 shows great state wise variation. While a state like Jharkhand has given out 10362 assistive devices, only 6062 persons with disabilities in Madhya Pradesh were given assistive devices in the same period. A large state like Rajasthan showed a distribution of 3868 assistive devices in a three-year period. Some smaller states and union territories like Puducherry, Lakshadweep and Arunachal Pradesh show no beneficiaries in the same period.[86]

The unevenness in distribution of budgets and people served is also perhaps an outcome of the fact that disability is a state subject, and it is the state that decides how important disability is to its development. However, it is critical that each state has a few basic services available for children and persons with disabilities.

New Initiatives

Through a few new initiatives, the Department of Empowerment of Persons with Disabilities is making strong attempts to include cross disability programming. This includes the Community Based Inclusive Development (CBID) program, which aims to create a pool of grass-root rehabilitation workers at community level who can work alongside Accredited Social Health Activist (ASHA) and Anganwadi workers to address cross-disability issues and facilitate inclusion of persons with disabilities in the society. This program has been started in collaboration with the University of Melbourne and has the possibility of taking services to children and not the other way round.

Similarly, the **new cross disability early intervention centres** set up at the National Institutes are another attempt to move away from a single disability approach.

Additionally, department of disability studies are being established in universities. Universities such as NALSAR (Hyderabad), Ambedkar University in Delhi, Tata Institute of Social Sciences (TISS) in Mumbai are all well known for their contributions towards creating an ecosystem of knowledge and discussions around disability.

Role of CBR

A study by Equals Centre for Promotion of Social Justice, Chennai, supported by ASTHA,[87] found that participation in CBR programs were critical for persons with disabilities. Many respondents interviewed believed that in the absence of CBR they would have been "stuck at home" - isolated and would never have an opportunity to come out and meet people. The study also cautioned that women with disabilities and persons with high support needs tend to get left out even in these programs.

The study points to the importance of Organizations of Persons with Disabilities (OPDs), Self Help Groups of parents and advocacy done by them at the community level. With regard to institutionalization, it points out that, "In case of persons with disabilities experiencing high restriction in participation, who are more likely to get institutionalized, some organizations have initiated programs like caregiver support groups, peer support groups, compensating Personal Assistant (PA) services and housing programs as part of their projects. Not all constituencies of persons with disabilities are at the same risk of institutionalization, particularly when the policy/legislation in India sanctions institutional care for persons with psychosocial and intellectual disabilities."[88]

Amongst other recommendation the study recommended that "CBID (Community-based Inclusive Development) with a specific focus on the habilitation and rehabilitation of persons with disabilities must be promoted as a flagship program both at the Union and at the state government levels.

Although there was an attempt by civil society made to introduce CBR in Mission Mode to the government, it did not fructify. What we do find is that at present most disability specific programming is not yet fully in line with the provisions of the RPwD Act 2016. The reach of government programming continues to be limited and there is large interstate variation in the provision of basic services.

Programs run by The National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities

The National Trust Act works through its registered organizations across the country, as well as the State Nodal Agencies and a network of Local Level Committees (LLCs) at the district level. The schemes are limited to the four impairment groups listed in the law and thus, their reach is limited in scope. Additionally, this Act has not yet been harmonized with the CRPD.

National Trust - Schemes for Children with Disabilities			
Scheme	**Centres**	**No. of Children Served from 2015-2016 to 2022-2023**	**Amount (Rupees in crores)**
Disha (Early Intervention and School Readiness Scheme for 0-10 years)	115	4141	14.46
VIKAAS (Day Care Scheme for 10+ years)	124	6918	25.13
Disha-cum Vikaas Scheme (Day Care)	42	5300	23.24
Samarth (Respite Care Residential Scheme	45	1975	11.97

Source: Department of Empowerment of Persons with Disabilities, GOI, Annual Report 2022–23 & 2021-22.

National Trust - Schemes for Children with Disabilities & Persons with Disabilities			
Scheme	**Centres/Claims**	**No. of People Served 2015-2016 to 2022-2023**	**Amount (Rupees in crores)**
Samarth-cum-Gharaunda (Respite Care Residential Scheme	12	926	6.17
Niramaya' Health Insurance Scheme	12641	165243	7.24

Source: Department of Empowerment of Persons with Disabilities, GOI, Annual Report 2022–23 & 2021-22.

The schemes continue to be centre based with the Samarth scheme being a residential care scheme. Samarth and Gharaunda together provide residential care to both children and adults. While the scheme is of limited reach and scope, and expenditures are relatively low, the intent behind the scheme is not aligned with the current thinking around deinstitutionalization. A child with a disability of school going age should not be in a day care situation nor should any child be in a residential care facility.

The Niramaya Health Scheme

The Niramaya Health scheme was an innovative attempt by the National Trust to create a service that caters to the needs of children and persons with disabilities. The insurance scheme provides financial support to meet costs for therapy, transport, etc., which are extremely critical in the rehabilitation of children in the impairment groups covered under the National Trust Act. However, the scheme offers limited coverage and is also narrow in its reach.

> ***"During the year 2022-23 (till 15.12.2022), a total number of 1,65,243 Divyangjans have been enrolled. Total 12641 claims settled amounting to Rs. 7.24 Crores. The expenditure during the year is Rs. 9.82 Crores. At present, the scheme is being implemented through M/s. Oriental Insurance Co. Ltd."- Department of Empowerment of Persons with Disabilities in its Annual Report[89]***

Current Situation of Implementation of RPwD Act 2016

The Rights of Persons with Disabilities Act 2016 is often termed as a paradigm shifting legislation. While the law demonstrates a commitment to inclusion, there are gaps in its implementation. In an order on the petition filed by Seema Girija Lal vs the Union of India on the status of implementation of the RPwD Act 2016, paragraph 2 of the judgement states, "The status of implementation of the legislation indicates a dismal position across the country."[90] Many states are yet to appoint independent State Commissioners for Persons with Disabilities. Several states had not notified their rules to the Act, and District Level Committees have not been constituted in some others. Similarly, appointment of nodal officers to oversee the education of children with disabilities in the district have not been appointed in Assam, Bihar, Dadra and Nagar Haveli and Daman and Diu, Goa, Jharkhand, Nagaland, Puducherry, Tripura. Over 16 states including Jharkhand have not as yet instituted assessment boards for children and persons with high support needs.

Disability Certificate and Unique Disability ID (UDID)

The disability certificate is the most critical document that all children with disabilities must have if they are to access any of the schemes and affirmative action set out by the law. Historically, the process of getting a certificate has been fraught with difficulties. These have included the lack of trained medical doctors to be part of the medical boards in public hospitals to assess the child, persistent delays in the process and difficulties in getting an assessment with multiple assessments and tests needed for some impairment groups, and the difficulties of using the certificate across different states of the country. These barriers have impacted the reach. Out of a total population of 2,68,14,994 persons with disabilities identified by the 2011 census, only 1,74,25,905 have been issued disability certificates as of 19/01/2022.[91]

In order to overcome these hurdles, the Department of Empowerment of Persons with Disabilities launched a holistic end-to-end integrated system for issuance of Unique Disability ID card and disability certificates which could be used anywhere in the country and would be the one document required to access all the affirmative actions for children and persons with disabilities. Children and persons who already have disability certificates now must surrender them and get the UDID card made. However, as the process is now online it could be a barrier for a large number of families who do not have knowledge of technology. There are reports in rural areas of Bihar of middlemen demanding up to five thousand for such a certificate.[ii]

Social Protection Scheme

The disability pension is a social protection scheme that has been operational since 1995. The government of India provides 300 rupees from its budget under the Indira Gandhi National Disability Pension Scheme to the state, with states having the prerogative to add additional amounts to it. There is, therefore, significant disparity in the amounts that are given by different states - from 2,500 in Delhi to 700 rupees in Jharkhand. Some states such as Assam and Madhya Pradesh do not have allowances for children.

[ii] Shared by parents of children with disabilities from rural Bihar during the launch of the Report of ASTHA and the RTE Forum Bihar on the situation of children with disabilities in education during the COVID 19 disaster.

There has been a consistent demand from the disability sector to increase this very important social protection scheme in line with the current levels of inflation and align it with the international poverty line. However, the allocation from the Union government for this scheme has remained almost the same over the years. In 2024-25 it was 290 crore rupees which was the same in 2023-24. A comparison with 2019-20, 2020-21 shows that previous years had an enhanced budget allocation of 300 and 347 crore rupees respectively. Another challenge is that it has been difficult to fully spend even these amounts.[92] Furthermore, the recent decision of the government that children and persons with disabilities can only avail the schemes if they have a UDID card can lead to even more challenges as many children do not have this card as yet.[93] The exact number of children who do have the UDID or disability certificate is not available in the public domain.

Section 4
Inclusion in Laws and Programs for All Children

Children with disabilities are children first. The CRPD and the RPwD Act 2016 reinforce this mandate for inclusion of children with disabilities in all areas of development and services for all children. It is, therefore, important that child centred programs and schemes also include children with disabilities.

The ecosystem of care for children who are at risk of family separation comprises the Juvenile Justice Care and Protection Act 2015 (JJ Act), its Rules of 2016 amended in 2021, the Adoption Regulations as well as the Model Foster Care Guidelines 2024. While children with disabilities are mentioned in the JJ Act, the test of how the law impacts them depends on how they align with the core principles of the CRPD and the RPwD Act 2016, and to some extent the Mental Health Care Act.

Children with Disabilities in the Context of Child Protection Laws

The vulnerability of children with disabilities to being ***concealed, abandoned, neglected and segregated*** is not new to India. From time to time, there have been public interest litigations (PILs) across the country about the grave barriers and human rights violations that children with disabilities face when placed in institutions. The continued institutionalization of children with disabilities in India has been a cause of concern to both the CRC and CRPD committee.

In 2011, Indian civil society submitted its first alternative report on the status of children with disabilities to the CRC committee. The report spoke of the "elaborate quasi-judicial system of Child Welfare Committees and the Juvenile Justice Boards set up throughout the country to see that speedy justice is given to children in need of care and protection and children in conflict with the law. Alongside this is an elaborate system of Childline (a countrywide helpline for children in distress), the state and district child protection societies, adoption agencies and homes that are supposed to house children who are abandoned, in distress, or in conflict with the law. Unfortunately, experience and study show that none of these agencies know how to respond to children with disabilities."[iii]

The report further points out that "serious human rights violations and conditions of shelter homes for children with disabilities have been reported sporadically in the media from all parts of the country."[94]

[iii] This is from a pilot study on Violence and Discrimination faced by Children with Disabilities conducted by AARTH-ASTHA for Plan India. During this study members of AARTH-ASTHA interviewed and held discussions with members of the Childlines and the Child Welfare Committees in Delhi. Most said they did not know what to do with children with disabilities. Lack of training, information and knowledge about entitlements, lack of staff, inaccessible facilities were some of the reasons cited for this. This information is available with the author of the report.

Behind the instances of violence, abuse and ill treatment lay many deep structural issues. The lack of knowledge and understanding of the specific requirements of children with disabilities, lack of individual care plans, no right to education, negligible rehabilitation services, no support facilities for recreation and play and vocational training or skill building activities characterize the majority of homes that have been studied and visited in different states in the country.[95] Adding to these, the lack of exit pathways has resulted in many children living in homes their entire lives.

The Case of Asha Kiran

In 2012, the Advisory Group to the Asha Kiran shelter home in Delhi wrote and submitted a report to the Supreme Court in the ongoing matter of Reena Banerjee vs Govt of NCT and others.[96] While the report highlights in detail the situation of children and persons with disabilities within the shelter home, the following observations focused more directly on aspects of care:

1. Lack of coordination between various bodies, committees charged with bringing in reform or protecting the rights of residents.
2. Lack of a unified vision for the rights of the residents and the services to be provided. The Commissions, the CWCs and the courts are unfortunately not cognizant of the rights of children and persons with disabilities as per the CRPD and do not know what to monitor.
3. No access to justice and no contact with the outside community.
4. Instead of only building more institutions like Asha Kiran, it is important that the state focus on reaching children with disabilities directly in their homes and communities with rehabilitation and all other supports and services, foster inclusion in education and all aspects of life and enable independent living for adults with disabilities within their homes and communities.
5. It is important that all policy makers begin to recognize the citizenship of children and persons with disabilities and ensure that the full range of rights are guaranteed even within institutions and not seen as an exception.
6. While immediate changes are important, a long-term perspective and plan needs to be drawn up.
7. It is important that we explore a whole range of options for alternate care and support of children and persons with disabilities without families and put schemes and strategies in place urgently, simultaneously with reform within the facility.
8. Every effort must be made to reintegrate children and adults with their families and/or communities.
9. There has to be greater support built into our programs and policies for families and children with disabilities.
10. There is a need to conceptualize and create schemes for alternative care which take into account the needs of children with disabilities.
11. There has to be greater effort now to create an exit policy. However, care has to be taken to see that such a policy is supported by policies and programs that support independent and assisted living within communities.[97]

A decade later, as the case lies dormant for years, Asha Kiran is once again in the news with deaths and maltreatment of children and persons with disabilities in 2024.[98]

The Jena Committee Report

The 2017 Jena committee report once again draws our attention to the lack of facilities and knowledge about care and protection of children with disabilities. This report came out of a countrywide study supported by the Ministry of Women and Child Development on the status of 9589 Child Care Institutions (CCIs) in India. It found that about 5 percent of all children in CCIs are children who are "*mentally and physically challenged*".[iv] There were 10794 (2.9 percent) *mentally challenged children* and 9040 (2.4 percent) *physically challenged children* in CCIs.[99] They represent a high percentage among the different categories of children who are in CCIs, with only children with single parents and orphans being above them. The report also highlights that children who are vulnerable such as children with disabilities, those with medical conditions and transgender children often go unnoticed in these homes.[100]

Study from Bihar

Another study conducted to assess the numbers and situation of children aged 15 years and above living in Child Care Institutions (CCIs) in the 9 divisions of Bihar[101] finds that almost 51 percent of the children in the homes studied were *children with special needs (CWSN)*.[v] Most children remain confined to services which are provided within the premises of the CCI and are not allowed to venture outside for education or vocational training. Specialized facilities for children with special needs residing in CCIs are completely lacking. In the absence of services such as special educator, therapies, instrument/equipment for therapies, hospitals and therapist for occupational, education, the study concludes that "the chances of rehabilitation and restorations of *children with special needs* are uncertain."[102]

The study recommends among others that:

- Children with disabilities need a specialized and extra intervention plan to make them independent. Children with disabilities residing in the CCIs require special intervention for training, both vocational and adaptive. This is especially true for persons with "*severe to profound disabilities*"[vi]. The CCIs presently house a large number of children with disabilities. There is an urgent need to initiate the process to identify the disabilities, and design and implement appropriate interventions. This assessment is also linked to acquiring disability certificate needed to help formulate effective aftercare plans.
- To make intervention effective and fruitful for children with intellectual disabilities, trained and certified professionals in relevant fields of specialization are required on an urgent basis.
- More in-depth and focused studies on the situation and needs of children with disabilities staying in the CCIs and aftercare home need to be undertaken with gender lens.[103]

[iv] The terms 'mentally and physically challenged' are not used by Keystone Human Services International or by the Children and Families Together -India program. This has been taken as is from the report.

[v] The term Children with Special Needs is not used by Keystone Human Services International or by the Children and Families Together -India program. This has been taken as is from the report.

[vi] The terms severe and profound are not used by Keystone Human Services International or by the Children and Families Together -India program. This has been taken as is from the report. The preferred terminology is 'persons with high support needs'.

Concern over Institutionalization of Children with Disabilities: Concluding Observations of the CRC and CRPD Committees

India has ratified both the Convention on the Rights of the Child (CRC) and the Convention on the Rights of Persons with Disabilities (CRPD) and had brought in laws to harmonize its national legislations to the respective Conventions. It has also taken several steps to ensure that the rights enshrined in the Conventions are translated into tangible programs and schemes on the ground. However, there are still areas that need attention. Both the CRC and CRPD committees in their Concluding Observations of their review of India's implementation of these Conventions, have expressed concern over the continuing institutionalization of children and persons with disabilities and given recommendations for the government to implement.

Committee on the Rights of the Child: Concluding Observations of the Combined Third and Fourth Periodic Reports of India[104]

While welcoming the National Early Childhood Care and Education Policy of 2013, which is intended to enable parents to better take care of young children, the Committee on the Rights of the Child (CRC Committee) expressed concerned about the lack of a national strategy and programs to support parents and families in fulfilling their child-rearing obligations, as well as the lack of family counselling and parenting programs, which increase the risk of neglect, maltreatment and abuse of children within the family.

The Committee acknowledged the State party's efforts to improve the alternative care system but it highlighted that institutionalization is still dominant instead of family-based care. It further highlighted:

- The lack of disaggregated data on children in need, children provided with services and in different forms of alternative care, support services for parents and kinship caregivers, abandonment, neglect and abuse of children and measures adopted, other than legislation.
- The lack of information on the assessment, selection, training, remuneration and supervision of foster parents and kinship caregivers, review procedures for children in care, as well as accreditation, minimum requirements for and supervision of children's homes and a complaint mechanism for children in public care, including State, private, NGO- or church-run facilities.

Recommendations

Among others, the CRC Committee recommended the following:

a) For India to establish adequate support services for parents, as well as adopt and implement awareness-raising and training programs on parenting skills, including on alternatives to corporal punishment.

b) Supporting and facilitating family-based care for children wherever possible and establishing a system of kinship care and foster care for children in alternative care, with a view to reducing the institutionalization of children.

c) Ensuring adequate safeguards and clear criteria, based on the needs as well as the best interests of the child, for determining whether a child should be placed in alternative care.

d) Ensuring independent and periodic review of the placement of children in foster care and institutions, and monitoring the quality of care therein, including by providing accessible channels for reporting, monitoring and remedying maltreatment and abuse of children.

e) Ensuring that adequate human, technical and financial resources are allocated to alternative care centres and relevant child protection services in order to facilitate the quality of rehabilitation and social reintegration of children resident therein to the greatest extent possible.

It must be noted that there have been progressive changes within the legislative and policy space in the country since this review. There is demonstrated commitment from the government of India to move away from institutional care to family based alternative care. This is evident in the implementation of flagship programs like Mission Vatsalya.

Children with Disabilities

While all the above recommendations are equally applicable to children with disabilities, the Committee flagged the high rate of abandonment of children with disabilities by their parents, the lack of coordination among relevant ministries in planning and implementing programs for children with disabilities as well as learning towards institutional care and medical treatment when it comes to children with disabilities.

In the light of article 23 of the Convention and of the Committee's General Comment No. 9 (2006) on the rights of children with disabilities, the Committee urged India to adopt a human rights-based approach to disability and specifically recommended that the government:

a) Develop a national plan of action for children with disabilities which integrates all the provisions of the Convention as well as indicators to measure outcomes and ensure effective coordination among relevant ministries for its implementation.

b) Allocate adequate human, technical and financial resources to support parents of children with disabilities with the aim of preventing the abandonment of children with disabilities.

c) Take adequate measures to ensure that children with disabilities fully enjoy their rights as enshrined in the Convention, including access to education, health care and social services.

d) Conduct awareness-raising and educational campaigns targeting children with disabilities, the public at large and specific groups of professionals, with a view to preventing and eliminating discrimination against children with disabilities.[105]

Committee on the Rights of Persons with Disabilities: Concluding Observations on India's Initial Report[106]

In its comments on the implementation of article 14 of the CRPD covering liberty and security of the person, the Committee on the Rights of Persons with Disabilities (CRPD Committee) highlighted the following:

a) Institutionalization of persons with disabilities on the basis of impairment, including in "mental health care homes", "custodial care institutions" and psychiatric hospitals, particularly affecting persons with intellectual or psychosocial disabilities, homeless persons with disabilities and persons requiring high levels of support, in the absence of measures to end all forms of institutionalization on the basis of impairment.

b) Confinement of persons with intellectual disabilities within their homes.

c) Incarceration of persons reported as "mentally ill" on the basis of impairment and the assumption of being unfit to stand trial.

Recommendations

The CRPD Committee made the following recommendations for India on the concerns highlighted above:

a) Allocate financial resources to ensure the inclusion of all children with disabilities in basic public services and support, including in early childhood, ensuring accessible early development centres for all children.

b) Ensure the effective protection of all children with disabilities under child protection scheme and other programs, prioritizing children in rural areas and children who face a risk of abandonment and institutionalization and strengthening measures to provide support in the community, including in foster families.

c) Adopt measures to enable children with disabilities to express their views in all matters related to their lives, including in administrative or judicial procedures.

d) Prevent the confinement of persons with intellectual disabilities within their homes and provide for human rights-based support and community services for all persons with disabilities on an equal basis with others.

e) Ensure the right of persons with psychosocial disabilities to due process and a fair trial in criminal proceedings and end the use of "criminal wards for the insane."

Rights of Children with Disabilities in the Juvenile Justice Act 2015, Rules 2016/21

While much progress has been made in the areas of child rights and disability rights, the findings so far indicate that there are still gaps when it comes to convergence. Children with disabilities are children first and must be accorded the same care and protection as children without disabilities. It is in this context that we must analyze the laws governing the protection system for all children, as to how they have addressed the needs of children with disabilities, including from the lens of the RPwD Act 2016 and the MHCA 2017. Mission Vatsalya, the scheme on the ground that directs implementation of the JJ Act, formal alternative care mechanisms like the Adoption Regulations 2022, the Model Foster Care Guidelines 2024 as well as the scheme for sponsorship must therefore be reviewed from this lens.

> ***A close look at all these documents reveals many inconsistencies in our approach to children with disabilities and their rights. The rights of children with disabilities have undergone a paradigm shift and this shift is yet to be adequately reflected in laws and policies relating to children.***

Confusion in Terminology used by Laws and Guidelines

The Juvenile Justice Act 2015, amended in 2021, the Model Rules 2021, the Adoption Regulations 2022 as well as the Model Foster Care Guidelines 2024 form the framework of childcare in India. However, when it comes to the issue of disability, they are not entirely aligned with the disability laws and policies.

The CRPD settled the continuing international and national confusion on how to address children and persons who are 'disabled' by referring to them as '*children and persons with disabilities*'. Addressing a child in this way brought our attention to the child first and then the disability. In India, the Rights of

Persons with Disabilities Act 2016 adopted the same terminology, although in subsequent years, the government started referring to children and persons with disabilities as '*Divyangjan*'.

While the JJ Act 2015 addresses children with disabilities in need of care and protection as "*mentally ill, mentally and physically challenged*,"[107] it's Rules adopted in 2022, refer to them as children who are "differently abled" in a few places, and children with disabilities in others. The Adoption Regulation acknowledges the RPwD Act of 2016 but puts children with disabilities under the larger category of *Special Needs Children* along with other vulnerable children. The Model Foster Care Guidelines too refer to the *Special Needs Child*.[vii] Using different terminologies for the same child in the same document can be extremely confusing for implementers of the law.

For example, Form 22[108] pertaining to the Social Investigation Report of the Child, includes questions on *neurological disorders, mental handicap, physical handicap*[viii] in the section on Health Status of the Child. The same form, in the next section, includes a question whether the child is *differently abled*. It then goes on to give options such as hearing impairment, speech impairment, physical disability, mental disability and locomotor disability.

This incongruency in formulations stands to create confusion at the implementation level. It also reinforces why meaningful consultation with persons with disabilities and their representative organizations is critical in policy and legislative processes, including when amendments are made to existing laws.

Implications for Children with Disabilities

The lack of convergence in the terminologies used for children with disabilities could mean:

- Lack of dignity in the way children are treated within the system, and in their rehabilitation and restoration efforts.
- Practice of multiple assessments that can further traumatize the child.
- Creation of barriers in the work of child protection functionaries as they may not understand how and where to place the child with a disability that enters into the system.

Some Omissions in the Law

In 2011, the Alternative Report[109] submitted to the CRC Committee by the disability movement flagged a few important issues. It said, "Although the Juvenile Justice (Care and Protection of Children) Act 2000 as amended in 2006 and its rules of 2007, identifies children with disabilities without family care as a group of children needing care and protection, there is nothing further in the Act to acknowledge the evolving capacities of the child, the supports and reasonable accommodation necessary for the child with disabilities to participate in legal proceedings or in the provision of care and protection." Similar omissions even in recent amendments of the Rules of the Law in 2022 point to a continued medical understanding of disability as well as the work that remains to be done to foster convergence. This can

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[vii] The terms Special Needs Children or differently abled are not used by Keystone Human Services International or by the Children and Families Together – India program. They have been taken as is from the cited documents.

[viii] These are not terms used by Keystone Human Services International or by the Children and Families Together – India program. They have been taken as is from the cited documents.

lead to grave implications for children with disabilities, where they may not find the required support which can force them to be entirely dependent on others for daily living activities, reinforcing the view that the child cannot do anything.

Practices in Institutionalization of Children with Disabilities

The JJ Act 2015/21 and Mission Vatsalya still have an underlying medicalized view of disability. For example, the scheme talks about putting all *children with special needs* in a specialized unit within a home and/or setting up separate homes for children with disabilities[110] as well as later on for "*women who are mentally challenged*".

> ***Section 93 of the JJ Act allows for transfer of a child who is mentally ill or addicted to alcohol or other drugs.—(1) "Where it appears to the Committee or the Board that any child kept in a special home or an observation home or a Children's Home or in an institution in pursuance of the provisions of this Act, is a mentally ill person or addicted to alcohol or other drugs which lead to behavioural changes in a person, the Committee or the Board, may order removal of such child to a psychiatric hospital or psychiatric nursing home in accordance with the provisions of the Mental Health Act, 1987 (14 of 1987) or the rules made thereunder".***

This opens the door for children to be separated or put into a psychiatric facility on the basis of a psychosocial disability. In 2011, section 58[111] of the JJ Act was amended. This amendment allowed children deemed to be mentally ill by a competent authority to be put into psychiatric nursing home or hospital as per the provisions of the Mental Health Act 1987. Such an amendment referring to a law that was, at that point in time, undergoing change as a result of India's ratification of the CRPD and one that relied heavily on institutionalization of persons with disabilities underlined the strong belief still prevalent in India that institutionalization and medical care are the only ways to rehabilitate children and persons living with mental illness.

In 2017 the Mental Health Care Act was enacted which repealed the Mental Health Act of 1987. The MHCA attempts to safeguard the rights of children with disabilities at every step in the event of institutionalization by laying down steps to be followed. There is an attempt to start with options other than institutionalization and clear checks and balances are spelt out in the law itself. Section 87 of the MHCA clarifies that the child can be put into a facility only when ***all community-based alternatives to admission have been shown to have failed or are demonstrably unsuitable for the needs of the minor.*** If a child is put into a hospital, a nominated representative of the same gender must stay with the child to represent the wishes of the child. Regular reviews of institutionalization are mandated in this section.

Even though the JJ Act and Rules have been recently updated, the references to the now repealed Mental Health Act of 1987 remain. This is bound to cause further confusion in the implementation as many people in the protection areas may not be aware of the new 2017 law and the progressive changes it brings about.

The Adoption Regulations 2022 also provide the adoption agency with the option to shift *children with special needs* "to any other **specialized institutions** run by any Government or non-government organisation" in the event that the agency finds that they do not have the "necessary facilities and means for their long-term care."[112] Furthermore, section 6 on the treatment of *children with special* *needs* allows for a medical examination of the *child with special needs* as they come into the facility. While this is very important for all children, there are other assessments and a holistic understanding of the child which seem to be missing.

Implications for children with disabilities

The current practices in institutionalization of children with disabilities stand to increase the chances of separation of children with disabilities into a specialized unit becoming a default option leading to further segregation. This approach also fails to take into account the huge diversity among children with disabilities and those with long term or terminal illness, and deprives them of a chance to be included with all children.

Shifting children who are already without family care to another institution is not the best policy for the mental health of the child. These considerations are often bypassed for children with high support needs as there may be a thinking that the child cannot think for themselves, which does not resonate with the RPwD Act 2016 and the CRPD, which both promote inclusion with disability specific services when required.

Underlying Thinking on the Abilities and Rights of Persons with Disabilities

One critical issue that needs more attention in the discourse on care reform is the right of persons with disabilities to be parents. While the CRPD in article 23 mandates States parties to "ensure the rights and responsibilities of persons with disabilities with regard to guardianship, wardship, trusteeship, adoption of children" and to "render appropriate assistance to persons with disabilities in the performance of their child rearing responsibilities,"[113] the JJ Act or the Adoption Regulations as well as the Model Foster Care Guidelines specifically keep persons with intellectual and psychosocial disabilities out of adoption or foster care chances.

> ***The JJ Act stipulates that "Notwithstanding anything contained in any other law for the time being in force, a child of mentally retarded parents or an unwanted child of victim of sexual assault, such child may be declared free for adoption by the Committee, by following the procedure under this Act."***[114]

Similar pronouncements have been made under the Adoption Regulations and the Guidelines for Foster Care.

Procedure for Adoption

The Adoption Regulations state that, "The procedure for declaring a child of parents with **mental illness** or **intellectual disability** as legally free for adoption by the Child Welfare Committee shall be done on the basis of a certificate reflecting mental disability of the parents from the medical board constituted by the Central Government or the State Government,"[115]

Model Foster Care Guidelines

The Model Foster Care Guidelines came in 2024, after the Rights of Persons with Disabilities 2016 and the Mental Health Care Act 2017 were enacted**.** Recognizing the ease with which a person with mental illness can be deprived of their liberty and family, the MHCA 2017 for example puts into place stringent steps, checks and balances that are to be followed in the event there is a need for removal of children below three years of age whose mother is receiving care in a facility. It states that the child shall ordinarily not be separated from her during her stay in such an establishment. Only in the scenario where there is a risk of harm to the child, or it is in the interest and safety of the child, the child will be temporarily separated but the mother will continue to have supervised access. The decision must be reviewed every 15 days.[116]

However, the same safeguards may not be reflected in the Model Foster Care Guidelines. In the definition of children with unfit guardians it includes children whose parents may be *mentally unsound*.[117]

Implications for Children with Disabilities

A blanket approach and assumption of 'incapacity' reflects the medical model of disability. It does not take notice of the range of supports put in place by both the MHCA 2017 and the RPwD Act 2016 for supported decision making and recognition of capacity of persons with disabilities. The implications for children with intellectual or psychosocial disabilities are worrisome as such an approach can effectively nullify the principle of evolving capacities of the child. There is likely to be little investment in children who are not seen as growing up to become contributing citizens of society.

There is a need for a more nuanced and individualized approach to such decisions, instead of painting all persons from a certain impairment group as the same and incapable of looking after children.

Child Care Institutions and Children with Disabilities

The Juvenile Justice Act and its Rules 2016/amended in 2022 contain a few mentions of support for children with disabilities within Child Care Institutions (CCIs). These include:

- Provision of wheelchairs, prosthetic devices, hearing aids, braille kits, or any other suitable aids and appliances as required, for *children with special needs*.
- Appropriate education, including supplementary education, special education, for *children with special needs*, in line with the provisions of the Right to Education Act.
- District Magistrates entrusted with verifying credibility, background and previous record of the CCI are advised to consider "safety, security, transportation and support and access for *differently-abled* children" in their recommendation.
- The Principal Rules of 2016 includes "accessible gender and age appropriate and disabled friendly toilets" in the requirements under physical infrastructure[118].

However, as we delve deeper, we find that there is very little in the way of monitoring of children with disabilities in the CCIs. Form 46[119] in the amended Rules (2022) on Inspection of Child Care Institutions does not detail the requirements as highlighted above. There is a detailed form for inspectors of institutions that only includes a parameter for facilities and support such as equipment, staff, teaching and learning materials for *children with special needs* who have "visual needs, intellectual needs, hearing needs". The requirements of physical accessibility or of reasonable accommodations for children who need them are missing. These become particularly important if children with disabilities are to access essential spaces such as toilets and be able to move easily and with dignity through all areas of the CCI.

When it comes to foster care, there are no such requirements included when group foster homes are to be examined.[120]

Opportunities

Participation in Child Welfare Committee

The amendments to the JJ Act Model Rules 2016 allow for the Chairperson and members of the Child Welfare Committee to be individuals with experience or a degree in "*special education for differently abled children*".[121]

Special educators are important, and their inclusion as prospective members of the Child Welfare Committees is to be welcomed and is indicative of the growing understanding of the Ministry of Women and Child Welfare on disability issues. It is also perhaps an acknowledgement of the numbers of children with disabilities in the system. However, special educators will need to be suitably trained on child protection and the intricacies of being a facilitator of a child with disability for their roles within the system to be effective.

Alternative Care

The Rights of Persons with Disabilities Act 2016 refers to children with disabilities without family care being placed with extended family and in the community. However, alternative care provisions within Mission Vatsalya for children with disabilities do not detail these priorities in adoption, foster care or sponsorship. It is important that children with disabilities are included in the ambit. Equally important is the inclusion of the child with disability in all activities for children in the community and the fulfilment of all intersecting rights.

There is currently a lack of schemes under the nodal ministry of disability, the Ministry of Social Justice and Empowerment, to strengthen communities and extended families to care for a child with disability in case of abandonment or if it becomes difficult for parents to take care of them. There are, however, significant opportunities to strengthen community gatekeeping through existing strong mothers' groups, Organizations of Persons with Disabilities (OPDs) and peer support for children and adults with disabilities that could provide a safety net for the child in a community.

Adoption

The Adoption Regulations of 2022 include several references to the adoption of *children with special need*s, which includes children with disabilities. But it is a reality that there is still tremendous lack of acceptance among potential adoptive parents to accept a child with a disability. Data shows that fewer than 50 *children with special needs* found a home within India in between 2019 to 2022, accounting for less than 1 percent of the total 9,443 in-country adoptions between 2019-20 and 2021-22. On the other hand, *children with special needs* comprised[122] 39.1 percent, 56.1 percent and 73 percent of the total inter-country adoptions in 2019-20, 2020-21 and 2021-22.

Only 11, 8 and 29 *children with special needs* were adopted in 2019-20, 2020-21 and 2021-22 respectively, even as the total number of applications for adoptions grew during this period. Maharashtra (159), Madhya Pradesh (124) and West Bengal (122) were the top three states in terms of *children with special needs* available for adoption.[123]

The Adoption Regulations 2022

The Adoption Regulations 2022 focuses on expediting the process for *children with special needs* to be made legally free for adoption.[124] From a reading of these provisions, it appears that the *child with special needs* will be made free for inter-country adoption by a foreign parent earlier than a "normal child". The general thinking is that *children with special needs* will not get adopted within the country as easily as they will by foreigners. One of the reasons for the lack of in-country adoption of children with disabilities could be the lack of support services either for the prospective parent or the child in the country.

Larger systemic issues point to the lack of availability of state adoption agency in every district of the state as mandated by the Regulations. This has recently been brought forward by the PIL Temple of Healing Vs Union of India. In an order from 2024, the Supreme Court has noted with concern that their order of having a Specialized Adoption Agency (SAA) in every district of the country by the end of January of 2024 had not been fulfilled by many states. States such as Chhattisgarh, Jharkhand, Arunachal Pradesh, Delhi, Gujarat, Himachal Pradesh, Haryana, Uttar Pradesh, Uttarakhand, Punjab and Telangana had SAAs in less than half of their districts.[125]

Foster Care and Sponsorship

The Guidelines for Mission Vatsalya mandate that every district should have a Sponsorship and Foster Care Approval Committee to review and sanction sponsorship (for preventive settings only) and Foster Care fund. The guidelines include children with disabilities in the list of children who can be eligible for foster care. Similarly, children with disabilities are also included in the list of children who can be given sponsorship.[126] Sponsorship in all its forms plays a critical role in keeping children at risk of family separation and at risk of abandonment from being institutionalized.

This is one area where convergence needs to be explored actively. It would be the role of the disability sector to bring to the notice of the child protection system and relevant committees those children with disabilities and families who are vulnerable. It is equally important that the committees have the knowledge of the kinds of vulnerabilities that can be faced by the child with disabilities and their family.

Aftercare

The report submitted to the Supreme Court by members of civil society and the respondents in the Asha Kiran matter attempted to draw attention of the Court to the grave issues in aftercare of children and persons with disabilities, if they are ever able to leave the institution.

> ***"Once they enter Asha Kiran people only leave when they die or when they are restored to their families. As in other institutions there is no automatic leaving after the age of 18 or 21... The fact that Asha Kiran is a closed-door facility with residents having little or no contact with the outside world leaves us with a frightening picture of residents, children and adults living within four walls only leaving at the time of death."***

Due to the many challenges in tracing families of children and persons with intellectual disabilities and also given the high levels of abandonment, very few residents (on average 35 a year) are actually reintegrated with their families. Many more boys than girls get reintegrated back into their homes and communities. Children with high support needs are invariably left back in the residential facility.

Even in the case where there are institutions for children with disabilities run by civil society, it has been seen that they are often moved to another institution as adults.

The lack of training for independent living, education and inclusion while they live in an institution are also important factors in the lack of readiness of young persons with disabilities to engage with the world once they are of age. There is a need to look closely at these issues and advocate for change.

Support for aftercare within Mission Vatsalya also needs to be reviewed as it may not be enough for young persons with disability.[127]

PIL in the Supreme Court

In January 2024, a Public Interest Litigation was filed in the Supreme Court seeking framing of a policy or guidelines to provide aftercare facilities to *mentally and physically challenged people* or those with terminal illness who have no one to take care of them once they turn 18. A bench of Chief Justice DY Chandrachud, and Justices JB Pardiwala and Manoj Misra took note of the plea.[128] The plea filed by KSR Menon refers to a provision within the JJ Act that deals with "child in need of care and protection". The Court issued notices to the Ministry of Women and Child Development and the Chief Commissioner of Persons with Disabilities with the Department of Empowerment of Persons with Disabilities in the Ministry of Social Justice and Empowerment and sought responses within four weeks. The PIL is ongoing.

SECTION 5
Intersecting Rights: Education and Health

Children with Disabilities in Education, Health, Protection

General Comment 5 of the CRPD Committee talks of the high costs of exclusion which "perpetuates dependencies and thus interference with individual freedoms".[129] The Guidelines on Deinstitutionalization also highlight the importance of early support and inclusion in education for children with disabilities as strategies to build supports in the community.

General Comment 4 of the CRPD Committee on article 24 (education) recognizes the intersectionality of all rights to achieve inclusive education for children with disabilities. It emphasizes the right to inclusive education for children who maybe in foster care or in care homes as too many persons with disabilities are "living in long-term institutional care, lacking access to community-based services, including education, right to family life, community living, freedom of association, protection from violence and access to justice."

It further states that the introduction of inclusive education in the local community must take place alongside a strategic commitment to ending the practice of placing persons with disabilities in institutions. It calls for States parties to note the role that exercising the right to inclusive education will play in building the strengths, skills and competencies necessary for all persons with disabilities to enjoy, benefit from and contribute to their local communities.[130]

Early Childhood Care and Development

With the National Education Policy of 2020, there is now a strong impetus for early childhood care and education (ECCE). The policy talks of universal access to high-quality ECCE across the country in a phased manner, but no later than 2030. The overall aim of ECCE would be to attain optimal outcomes in certain domains such as physical and motor development, cognitive development, the development of communication and early language, literacy, and numeracy.

With the reorganization of the stages of education, children will now enter school at the age of three at what is called the foundational stage. The foundational stage spans five years, three years of Anganwadi and classes one and two. With this move the Anganwadi system of the Integrated Child Development Services (ICDS) becomes an important part of the education system.

The policy states that ensuring the inclusion and equal participation of children with disabilities in ECCE and the schooling system will be accorded with the highest priority. The policy endorses the provisions on education in the Rights of Persons with Disabilities Act 2016.[131] There is now, for the first time, a curriculum framework for Cross Disability Early Intervention and School Readiness produced in collaboration between the Rehabilitation Council of India and Pratham.[132]

For children with disabilities, access to early childhood intervention and education has been a challenge in the absence of any countrywide system for education and rehabilitation. There have been attempts in different states by civil society to train Anganwadi workers and to include children with disabilities in the system, but this has not been a government mandate. Therefore, inclusion has been sporadic and on a small scale where efforts have been made. In 2023, the Ministry of Women and Child Development produced an Anganwadi Protocol for Divyang Children,[133] which for the first time talks about early detection, inclusive Anganwadi and lays out the responsibilities and roles of frontline workers such as Accredited Social Health Activist (ASHA), Auxiliary Nurse Midwife (ANM) and the Anganwadi workers. As states start rolling this out and training their workers, there is a great opportunity here today to support and facilitate the inclusion of children with disabilities in this countrywide system. This can also be seen as the beginning of support services for children being made available where they live and close to their homes.

In 2013, the Ministry of Health and Family Welfare started the Rashtriya Bal Swasthya Karyakram (RBSK). Through this program, district early intervention centres (DEICs) started to work with children in the 0-18 age group. The RBSK focused on the four Ds (Defects, Disease, Developmental Delays, Disability). The program screened children for the four Ds through ASHA worker at Anganwadi centres and at schools. The DEICs usually located in the district hospital would also provide early intervention services.

With only 315 District Early Intervention Centre,[134] this important program is still small in its reach and needs strengthening across the country.

Of the impairment groups included in the RPwD Act 2016, a significant number are early childhood conditions. These include, for example, children with cerebral palsy, muscular dystrophy, Autism, dwarfism, intellectual disability, specific learning disabilities, and blood disorders. Children are also born with some forms of hearing and vision impairment, multiple disabilities, deaf blindness, speech, and language disabilities or may acquire these conditions during childhood.

Early childhood is also the time that these groups of children can adapt quickly to their conditions if they have access to rehabilitation services, assistive devices, training in communication systems such as sign language, support in movement and mobility and early stimulation and support. Unfortunately, these services that are specific to the child with disabilities are very small in scale and not available close to the child's home. For young families with young children with disabilities, this lack of services is a big barrier in enabling their child's development.

Learnings from ASTHA's early childhood programs in urban slums of Delhi

ASTHA is a 30-year-old community-based and cross-disability organization based in the slums of Delhi. The following are some of the learnings based on their years of work with the community.

Early Identification and Intervention

- Screening has led to the early identification of children with disabilities, allowing timely interventions. The screenings are done at community level in Anganwadi centres and can be done quickly. This along with individual sessions, group sessions and inclusive sessions has enabled many children with delays and disabilities to access Anganwadi and school at the right age.

Enhanced Capacity Building

- Extensive training sessions for parents, Anganwadi workers, and ASHA workers have enhanced their understanding and sensitivity towards children with disabilities. This has resulted in improved identification and better inclusion of children with disabilities in community activities and educational settings.

Social Empowerment

- Efforts to provide legal documents, such as disability certificates, Aadhar cards, and bank accounts, have empowered families and ensured that children with disabilities have access to necessary social rights. This has improved their access to education and other community resources.

Family Strengthening

- Sensitizing and training family members of a child with a disability about their needs is the starting point of the rehabilitation and building community support systems.[135]
- Addressing self-esteem, confidence, motivation, self-belief, positive attitude of not only the child, but the family plays an important role towards a child's home based and community-based rehabilitation.[136]
- Bringing mothers and caregivers together on a regular basis for learning and sharing has the important effect of creating peers supports for parents who may be going through an emotionally vulnerable time.
- There are always mothers, parents, grandparents who will become strong leaders in their community if supported. These are invaluable resource persons to champion inclusion.
- Bringing children with disabilities and children without disabilities together in play sessions and celebrations brings about inclusion naturally in the communities.
- Anganwadi workers and ASHA workers are very important first responders in the community and know each child in their community. With some support, they are able to identify and refer children with disabilities and include them in their classes for children.

Education

The Right of Children to Free and Compulsory Education (RTE) Act 2009 made the education of children in the 6-14 years age group a fundamental right. This includes ***all*** children including children with disabilities and those with high support needs. The law includes children with disabilities under 'disadvantaged groups' and references the Persons with Disabilities Act of 1995. However, the law also brought home based education for children with multiple disabilities and high support needs. This was not in line with the demands of the disability movement.

The Rights of Persons with Disabilities Act 2016 brought in extensive provisions on the education of children with disabilities. For the first time, a definition of inclusive education was outlined in the law.

> ***"Inclusive education" means a system of education wherein students with and without disability learn together and the system of teaching and learning is suitably adapted to meet the learning needs of different types of students with disabilities."***[137]

The RPwD Act also mandated that governments and local authorities should endeavor to make all educational institutions funded or recognized by them provide education to children with disabilities and went on to outline the steps and building blocks that will be required to do so. These include non-discrimination in admissions, the provision of reasonable accommodation and individual support, accessibility in school campuses and transport for children with high support needs.

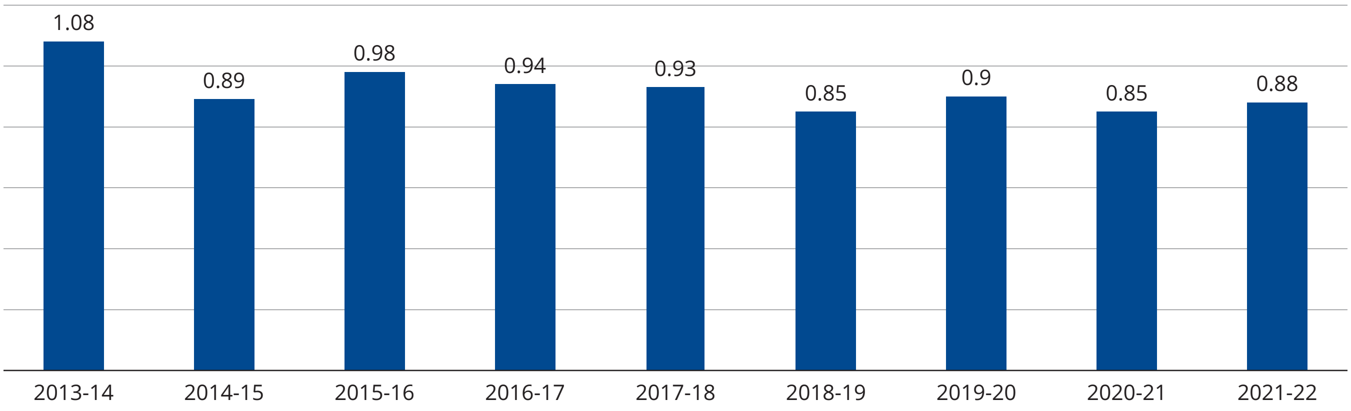
The law acknowledged that children with disabilities will communicate in different ways and calls for the promotion of Sign language, braille, alternative and augmentative communication (AAC) for students who require them. Recognizing the fact that teachers with disabilities are important role models in the system and that they would have skills like Sign language or know braille and be able to teach in these modes of communication, the RPwD Act 2016 talks about the appointment of persons with disabilities as resource persons and special educators to cater to the needs of children with disabilities.[138]

Despite progressive movement towards inclusive education, the RPwD Act 2016 continues special school and gives children and parents an option of choosing between a special school and a mainstream one. In effect, children with disabilities become one set of children who have multiple sites of education: the mainstream school, the special school, home based education, the Anganwadi system and the open school system. This runs the risk of lack of parity in standards and education for the child across the different sites.

With law and policy actively promoting the rights of children with disabilities, it becomes important to look at the ground level realities and the barriers within the education system.

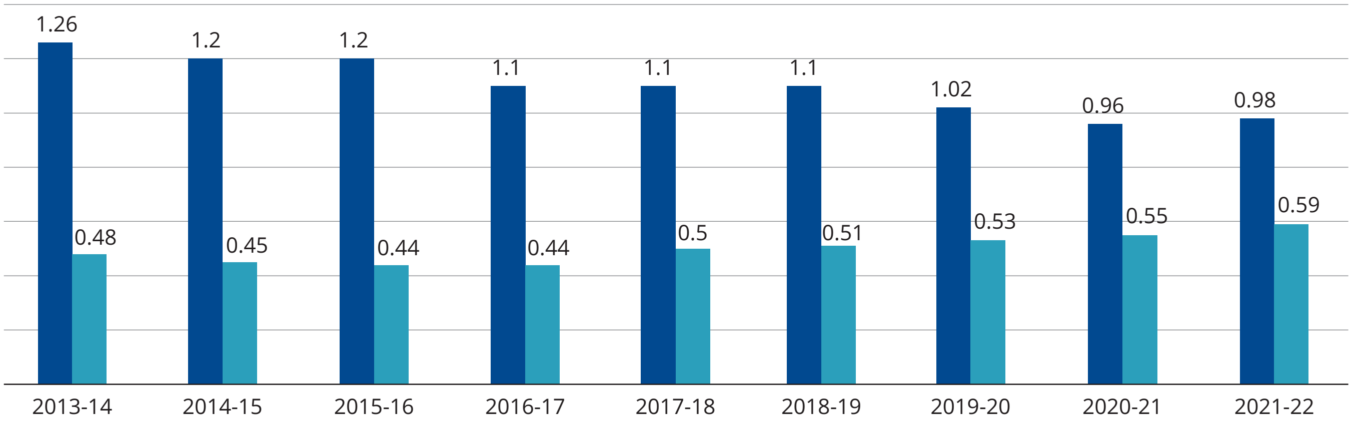
Data tells us that the enrolment of children with disabilities has remained stagnant and below one percent for over a decade. This has happened even as many new children with disabilities are now to be counted within the system after the RPwD Act 2016 expanded the definition of disability.

Percentage of Children with Disabilities to the Total Enrollment in School Education



Source: UDISE+ 2013-14-2019-20 Table 3.1 & Table 3.11 & 2021-22 Report Table 5.1 & 5.11.[139]

Percentage of Children with Disabilities to the Total Enrollment at Elementary & Secondary Level

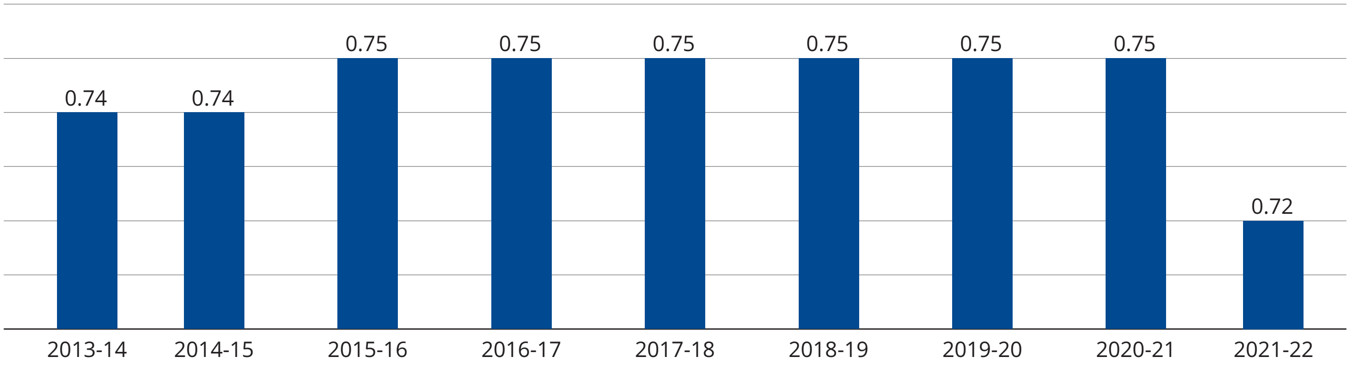


Source: UDISE+ 2018-19,2019-20,2019-20 Table 3.1 & Table 3.11 & 2021-22 Report Table 5.1 & 5.11.[140]

The other significant finding that the U-DISE data highlights is the big drops in enrollment of children with disabilities from elementary to secondary level. These steep drops indicate that at present there is much work to be done in the retention of children with disabilities in schools.

Girls with disabilities continue to remain vulnerable in the education system and specific effort has to be made to see that they are enrolled and continue to go to school. The Gender Parity Index (GPI) continues to hover between 72 to 75 girls getting enrolled in relations to boys with disabilities.

Gender Disparity in Enrollment of Children with Disabilities



Source: UDISE+ 2013-14-2019-20 Table 3.1 & Table 3.11 & 2021-22 Report Table 5.1 & 5.11.[141]

A recent report titled 'Present but forgotten'[142] on access to schools for children with disabilities gives us some indications of the challenges and enablers they encounter in government schools in India. The study was based on interviews with 947 parents of children with disabilities across 23 states of India through the collective effort of 41 organizations and individuals.

Some of the findings include:

- 60 percent of the parents said that they faced no difficulty in getting admission and in getting to schools, but once they are in school, children seem to face difficulty in accessing the whole school, in accessing materials in different formats and in participating fully in all activities of the school.

- While 45 percent of students required accessible learning material such as books in braille, large print, audio, or digital formats, only 17 percent were provided with these by the school. Sixty-four (64) percent of these students still could not study because the formats available were not accessible to them.

The report draws attention to the grave difficulties that children with rare diseases, and extensive medical requirements face in schools. Some of the conditions included in the rare disease group, like children with muscular dystrophy and blood disorders (thalassemia, haemophilia and sickle cell disease) are also included in the discussion on children with rare diseases in the National Policy on Rare Diseases launched in 2021[143] and parent groups advocating for the right to education and the recognition of children with rare diseases. The National Policy on Rare Diseases advocates monetary supports to children with rare diseases. As a result, Centres for Persons with Rare Diseases have been started in various hospitals in the country including the All India Institute of Medical Sciences (AIIMS) in Delhi.

> ***"A child with a rare disease is often denied access to schools, both private and public. They do not have any identity card, reservations and their medical conditions are unpredictable. This makes the school institutions shy away from giving admissions which becomes the single biggest obstacle in access to education for the children with rare diseases." - Organization for Rare Diseases India (ORDI), Bengaluru***

Another report on the experiences of children with disabilities and children requiring regular medical care navigating the education and health systems draws attention to the need of convergence between the education and health sectors and the importance of support structures for families and children.[144]

The larger issues in school education like the closure and merger of thousands of government schools across states, the increasing privatization of education and the lack of quality education in schools are the other challenges that require work and understanding in relation to the education of children with disabilities.

Health

The health system is the first system that parents of children with disabilities access when they need to understand why their child is showing delays or has functional limitations. Whether the child is born with an impairment or acquires it at a later stage, it is the health system that is the first that families must access. As such, this system has a great responsibility in guiding the family correctly and ensuring that there is access to holistic development. The fact that disability is a lifelong condition that cannot be cured with medical intervention has to be communicated to parents by the medical fraternity and it is therefore critical that they understand the nuances of disability.

Health for children with disabilities is not just about specific health issues that the child may face because of their condition. Children with disabilities also have similar health needs as children without disabilities and the same indicators of health for all children affect children with disabilities equally and sometimes even more. For example, children with disabilities are at greater risk of missing out on vaccinations than their peers without disabilities. Coverage of basic immunization against vaccine-preventable childhood diseases is significantly lower for children with multiple disabilities.[145] Additionally, children with disabilities suffer disproportionately higher rates of malnutrition.[146]

While all these facts about the health requirements of children with disabilities are well documented and field experience would corroborate these findings, there is little countrywide data or programming that supports actions to address them. For example, there is no segregated data on how many children with disabilities have had their full vaccination or how many are malnourished in the large mission mode programs on vaccinations or nutrition.

The study [147] on the intersections of health and education for children with disabilities with extensive health needs details the barriers families of children with thalassemia, multiple disabilities and children who had contracted Japanese encephalitis face in accessing the health system. These include:

The long route to diagnosis and treatment: Parents talked about doctors in their villages/towns being unable to understand the condition of the child. Eventually they had to go to the city or find a specialist hospital that made a correct diagnosis. In the bargain much precious time was lost.

Lack of healthcare facilities in rural India: Due to the lack of adequate services in the rural areas, many families have to shift to the city. Sometimes families have to break up, with one parent going with the child and the other remaining in the village or town.

Lack of information regarding treatment process, condition of the child and government assistance: Once in the big hospital, families share that there is a complete lack of flow of information to the parents and to the child (in age-appropriate way) about the condition, the course of treatment, what it entails, the likely consequences, the follow-up required and the impact it is likely to have on the child. There is also a lack of knowledge about the schemes for treatment that may be offered by the state or central government and the hospital may not give out the information proactively.

Socio- economic costs: Families spoke about the costs for commute, cost of living in another city, transport costs as additional expenses that many cannot afford. Other expenses often include treatment costs, costs for assistive devices, costs of therapies and blood transfusion for children with blood disorders and more. Most of these are out of pocket expenses if there are no schemes and support to offset them.

SECTION 6

The Situation of Children with Disabilities in Jharkhand

Jharkhand became the 28th state under the Republic of India on November 15, 2000. The state shares its border with West Bengal to the east, Chhattisgarh to the west, Uttar Pradesh to the northwest, Bihar to the north and Odisha to the south. **With 24 districts, Jharkhand is a state with a large tribal population**. According to the Census 2011, 26.21 percent of the population is tribal. The districts of Gumla[148] (68.94 percent), Khunti (73.25 percent), Simdega (70.78 percent) and West Singbhum (67.31 percent) have some of the highest concentration of the tribal population in the state. This means that the majority of children with disabilities in the state are tribal children following the customs of the tribal population.

Jharkhand faces low levels of development and is placed lower in the sustainable development index. While India's overall score on the Sustainable Development Goal Index prepared by NITI Aayog, stood at 71 in 2023-24 compared to 66 in 2020-21, with significant progress made on eliminating poverty, providing decent work, economic growth, climate action and life on earth, the states of Bihar, Jharkhand, Nagaland, Arunachal Pradesh have been placed at the bottom of the index.[149]Many challenges beset the children of the state. These include poverty, migration to other areas for work, child labour, child marriage and trafficking of children.

According to the Census 2011, which analyzed the percentage of scheduled castes (SC) and scheduled tribes (ST) amongst children and persons with disabilities, the proportion of persons with disabilities among the ST population in relation to the total number of persons with disabilities in the state was at 23.40 percent or 1,80,193 persons. This means almost a quarter of the population of persons with disabilities are tribal people, most of whom are in the rural areas. This figure is likely to increase in the next Census given the expanded definition of disability in the RPwD Act 2016.

As in other tribal areas, sickle cell anemia is endemic in Jharkhand. According to the health department of Jharkhand, sickle cell anaemia is highly prevalent in Gumla, Saraikela and Khunti districts of the state. These districts have historically been malaria-endemic regions, resulting in numerous deaths. Khunti district has a predominant rural population (91.54 percent), a majority of them belonging to ST (73.25 percent). Tribal groups such as Munda, Oraon, Lohra, Chik Baraik and Mahli are prone to getting sickle cell disease.150

Thalassaemia is another blood related health condition that is said to be endemic in Jharkhand. Both sickle cell anaemia and thalassaemia are said to have a prevalence rate of 8 to 10 percent which is double the national average and is considered as endemic zones for this disease.[151] Both are conditions that may require the child to have blood transfusions on a regular basis. Children with disabilities with these conditions are children who have extensive medical needs.

Disability Policy

Although India has a National Disability Policy of 2006, very few states have drafted their own State Disability Policy. Jharkhand was one of them. The Jharkhand State Policy on Disability framed in 2013-14 was a very progressive policy. It speaks of the need to facilitate the inclusion of disability rights in the strategies of the government, to develop an integrated management system for the coordination of disability planning and its implementation, and finally, to develop a comprehensive plan of action that will include among other things, a strong public education system and awareness raising programs. The policy focuses mainly on the following areas:

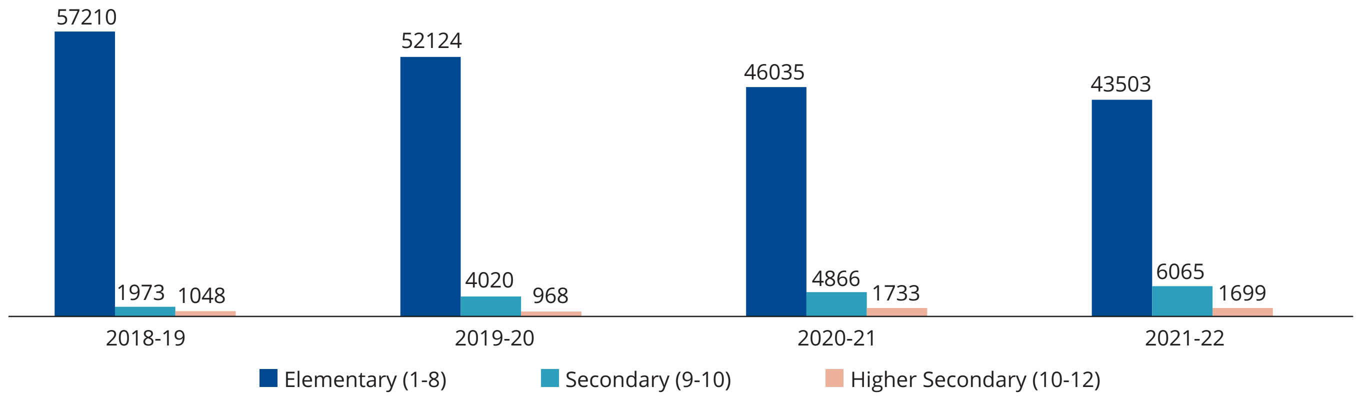
- Public education and raising awareness
- Prevention of disabilities through early identification and intervention, immunization, healthy lifestyle promotion among others
- Health care and nutrition
- Community Based Rehabilitation
- Barrier-free access
- Accessible and flexible public transport system
- Inclusive education
- Employment and economic empowerment
- Participation in public life
- Skill development through special vocation training services
- Human resource development to ensure access to necessary rehabilitation services
- Social Security
- Housing
- Cultural and creative activities and sports
- Data gathering and research on persons with disabilities
- Focus on mental illness, sensory and multiple disabilities, women and girls with disabilities and certification

This very progressive policy, unfortunately, is no longer in the public domain and although there is news of a new policy, disability groups in the state feel that the old one still prevails.

Education of Children with Disabilities

Data from the Jharkhand Education Project Council shows that many children with disabilities are hidden and deprived of their entitlements. As per Census 2011, total number of children with disabilities in the age group of 6-18 years in the state is 1,48,043 which constitute 1.71 percent of the general population.[152] There is a lack of updated and recent data but what continues to be available is the Unified District Information System for Education (UDISE) data on education which gives us information for analysis and further work.

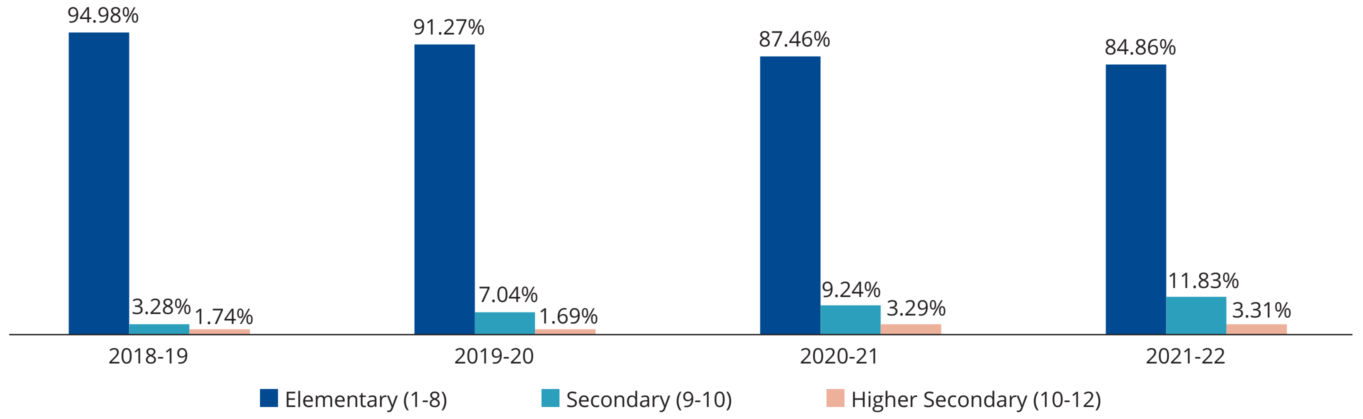
Number of Enrollment of Children with Disabilities in Jharkhand



Source: UDISE+[153]

As with most states and in line with the national trend, children with disabilities are entering schools in Jharkhand but there are steep falls in secondary and then higher secondary education. UDISE data from 2018-19 to 2021-22 show a slight improvement in the sharp falls in enrollment of children with disabilities from elementary to secondary to higher secondary. However, over 60 percent of the children who were enrolled in elementary education in 2021-22 did not stay on to go to the next level of schooling. There is therefore a need to understand why children are unable to stay on.

Percentage of Enrollment of Children with Disabilities in Jharkhand

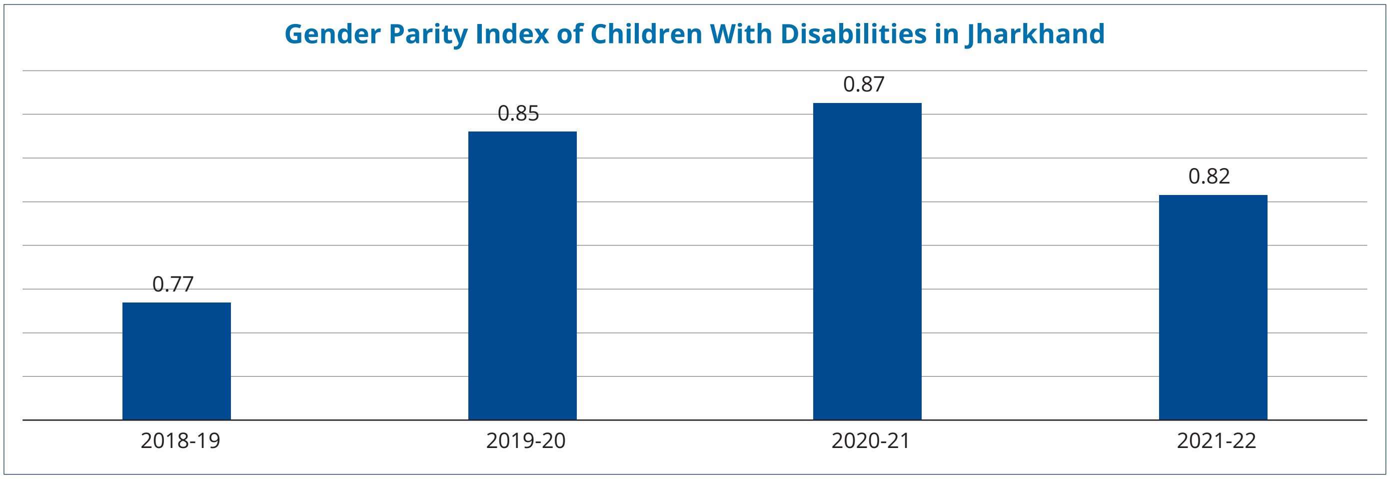


Source: UDISE+[154]

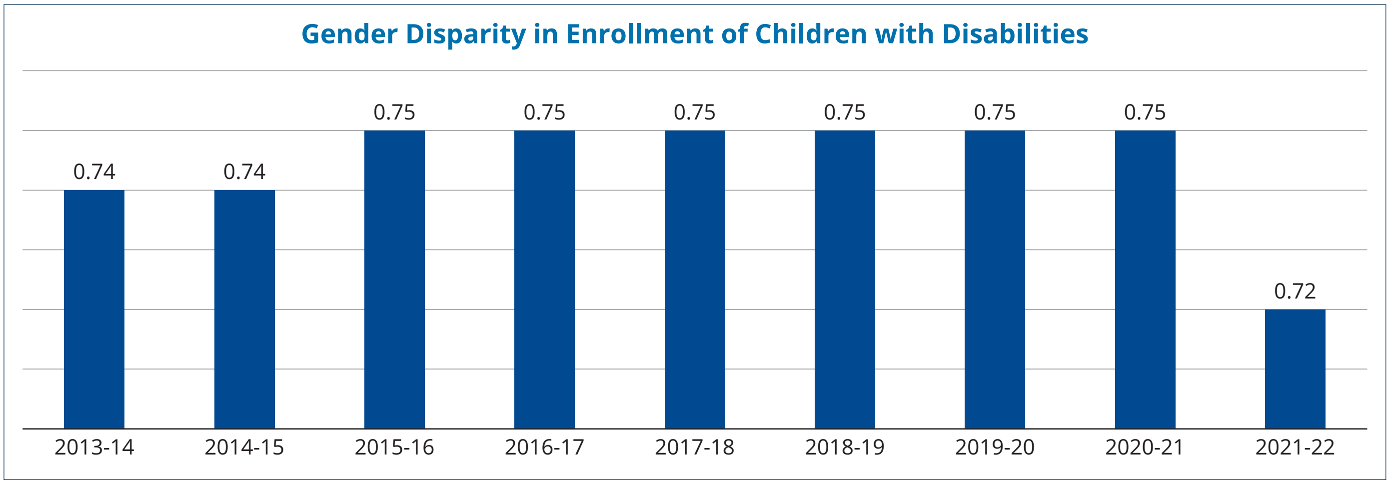
A recent civil society report on access to education points out that across states of Uttar Pradesh, Maharashtra and Jharkhand, physical barriers in educational institutions emerged as the leading cause of inaccessibility to educational spaces.[155] In Jharkhand 31.4 percent of the respondents talked about physical barriers in education.

Girls with Disabilities

In relation to the national picture where fewer girls with disabilities have been entering education for years, UDISE data show that there are many more girls who enter schools in Jharkhand than the national average. While the national average remains at 75 girls to 100 boys entering schools, Jharkhand does better with 80 to 85 girls with disabilities in schools in relation to a hundred boys.


Gender Parity Index of Children With Disabilities in Jharkhand

Source: UDISE+[156]


Gender Disparity in Enrollment of Children with Disabilities

Source: UDISE+[157]

The Jharkhand Right to Education Act Rules

The Jharkhand Right to Education Act Rules were notified in 2011. These outline the roles and responsibilities of the School Management Committees (SMCs) that are powerful legal bodies with representation from the community and parents of children. In the section on composition and functions of the SMCs, it underlines the role to monitor the identification and enrollment of and facilities for education of children with disabilities and ensure their completion of elementary education.[158]

In the section on duties and responsibilities of the state government and local authorities, the Rules clarify the responsibility of the state toward children with disabilities. It calls for the government or the local authority to make appropriate arrangement to enable them to attend school and complete elementary education.

It also mandates the state government or the local authority to undertake school mapping and identify all children, including children in remote areas, children with disabilities, children belonging to disadvantaged groups, children belonging to economically weaker sections for determining the requirement for establishing neighbourhood schools.

The lack of functioning and strong SMCs are another barrier to the rights to education of children with disabilities. Although experience shows that most SMCs in the country do not receive any training on the rights of children with disabilities, this is an opportunity for civil society to work with them and press for the inclusion of children with disabilities in schools. Other strategies used by civil society include preparing strong parents to become members of the SMC.

Merger and Closure of Government Schools

As with other states in the country, the government of Jharkhand merged 4,600 primary schools in 2017-18. The government is now planning to shut over 6,466 middle schools (classes 6 to 8) with less than 100 students. These schools would be merged with upgraded high schools in phases, starting with the institutions which have less than 50 students.[159] While the merger and closure of government schools is a trend all over the country, for children and particularly children with disabilities, such changes pose a great accessibility issues as schools move further away. For children who already face many barriers in reaching schools, greater distances can mean dropping out unless transportation is provided.

Implementation of the Rights of Persons with Disabilities Act 2016

Although the RPwD Act 2016 represents a paradigm shift in disability inclusion, states have been slow to comply. In a recent Public Interest Litigation (PIL) on the implementation of the RPwD Act, Jharkhand seems to be missing some vital elements for effective translation of the law into action. These include:

- Absence of an independent commissioner for persons with disabilities
- Absence of a Nodal Officer in District Education office
- Absence of an Assessment Board for high support needs

The lack of a State Commissioner for Persons with Disabilities was evident during visits of the Children and Families Together – India team to Jharkhand. This is also an indication of a slowdown in the implementation of the RPwD act in the state. The role of the Commissioner is also to monitor the implementation of the Act. Without an ombudsman like this the rights of children with disabilities cannot be taken forward.

Scheme for Implementation of the Rights of Persons with Disabilities Act 2016

According to the Annual Reports of the Department of Empowerment of Persons with Disabilities,[160] no grant-in-aid was released to institutions or organizations for persons with disabilities under the SIPDA scheme in Jharkhand for the years 2020-21, 2021-22, 2022-23.

Deendayal Disabled Rehabilitation Scheme (DDRS)

The following table demonstrates the number of proposals received, sanctioned, fund released, and people reached under the DDRS scheme in Jharkhand during 2018-19 and 2022-23.

	Proposal	Sanctioned	Fund Released (Rupees in lakhs)	Beneficiaries	NGO	Grant-in-Aid released to NGO
2018-19	1	0	1.59	0	0	0
2019-20	1	0	10.39	64	0	0
2020-21	0	0	0	0	0	0
2021-22	0	0	0	0	0	0
2022-23 (as on 31-12-22)	0	0	0	0	0	0

Source: The Department of Empowerment of Persons with Disabilities, GOI, Annual Reports-2021-22- Annexure 7A, 7B, 7C, 7D & 2022-23- Annexure 6A, 6B, 6C, 6D.[161]

District Disability Rehabilitation Centre (DDRC)

One DDRC was sanctioned in Hazaribagh in 2022-23.[162]

Scheme for Assistance to Disabled Persons for Purchasing/Fitting of Aids/ Appliances (ADIP)

The following table provides details of camps conducted, funds utilized, and number of persons covered under various activities from 2019 to 2022 under the ADIP scheme in Jharkhand.

	No. of Camps	Funds utilized (Rupees in Lakh)	No. of Beneficiaries
2019-20	2	103	216
2020-21	16	162	2,066
2021-22	204	294	4399
2022-23 (as on 31-12-22)	38	595	10,362

Source: The Department of Empowerment of Persons with Disabilities, GOI, Annual Reports 2022-23. Annexure-8 A.[163]

Details of Special camps held on demand during 2022- 23 (until 31.12.2022) based on the proposals received from Members of Parliament and other dignitaries under ADIP Scheme.		
	Number of beneficiaries covered	**Funds utilized (Rupees in Lakh)**
Khunti, Jharkhand	841	78.87
Palamu, Jharkhand	1,014	122.01
Ranchi, Jharkhand	196	14.43
Bokaro, Jharkhand	184	14.49

Source: The Department of Empowerment of Persons with Disabilities, GOI, Annual Reports 2021-22- Annexure-9A & 2022-23-Annexure-8 A.[164]

The data suggests that budgets for schemes and services for children and persons with disabilities have been low and uneven across different schemes. It is unclear why there has hardly been any proposal for work from the state to the central government for almost three years. Recently one DDRC has been sanctioned, and assistive devices are going on a regular basis to children and persons with disabilities in the state through the ADIP scheme.

When it comes to disability certificates and UDID cards, the state seems to be issuing low numbers till 2023.

Position of Issuance of Disability Certificates

Report of the Department of Empowerment of Persons with Disabilities shows that as of January 2023, 4,93,012 disability certificates have been issued by the state government in 24 districts. Additionally, 1,40,572 UDID cards have been generated in 24 districts[165]. Jharkhand has big government hospitals at the district level where disability certification is done. However, since the government has made the application process completely online, there seems to be a barrier for people who are not conversant with technology. There are reports of disability certificates costing Rs. 5000, whereas the process should not cost any money.

The Juvenile Justice System and Children with Disabilities

The Child Welfare Committee (CWC) is a powerful body that takes some very important decisions regarding the lives of children who are vulnerable. As such, it is important that they understand disability issues from a rights perspective and are trained on the nuances of disability.

While the experiences[ix] of the CWC in districts such as Ranchi are very different from those in the rural areas such as Gumla and Khunti, the lack of knowledge and training to address issues of children with disabilities cuts across all three districts. The Child Care Institutions (CCIs) where children with disabilities are sent also seem to have little understanding of the great paradigm shifts that have taken place in disability rights. This is not surprising as the JJ Act itself is not aligned with the RPwD Act and it is unclear on how children with disabilities are to be treated.

The deep underlying medical notion of disability is reflected in the fact that many parents will bring their children with intellectual disabilities and mental illness to Ranchi where there are two big hospitals in the hope of a possible cure. The Ranchi Institute of Neuro Psychiatry and Allied Sciences (RINPAS) is one of the oldest tertiary care centres in eastern India. It houses people with mental health conditions and is the base for the district mental health societies under the Mental Health Care Act 2017. Driven by the commonly held view that a medical cure is the only way to treat a child with intellectual disabilities or mental health conditions, parents and families come to RINPAS from across the state as well as the adjoining states. This is true for the Central Institute of Psychiatry (CIP) as well. However, when parents find out that the treatment is more long term, expensive and that they may have to stay with their child during the treatment, there are instances where they end up abandoning the child. This seems to be largely parents who are poor, who have to work and have other children whom they need to look after. According to the CWC, there are many such children on the streets of Ranchi.

The CWC members emphasized that recent changes of practice in the hospitals such as “no longer using shock treatment” and parents or a caregiver having to stay with the child being treated have led to an

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[ix] The Children and Families Together – India met with CWC members and other child protection functionaries. The experiences outlined in this section are from these key informant interviews and meetings.

increase in the numbers of children with disabilities being abandoned. They felt that the Mental Health Care Act 2017 was drafted without much consultation with stakeholders and that these conditions need to be reversed.[x] This shows that there is an urgency in implementing the transformative provisions within the RPwD Act or the MHCA by creating support services, as without these, the provisions could be perceived to be more detrimental to the cause of children with disabilities.

The CWC shared that they do not see many children with disabilities in rural areas. Interviews with parents of children with disabilities in Gumla lead us to understand that they are at a very limited knowledge of services for children with disabilities. Although they had some knowledge of disability certificates, they had no idea of the process. It appeared that at present there is little knowledge in the rural areas about the rights of children with disabilities and they continue to be hidden.

In Gumla, the CWC have seen cases of abandonment. There is a traditional acceptance of remarriage in the area if one spouse dies. In many such cases of remarriage, the CWC found that the children are left in the grandparents' care. These children with single parents are often seen abandoned in the area. According to the Child in Need Institute (CINI), rural and tribal areas of the state are witnessing a breakdown of traditional tribal ways of child-rearing. Poverty, substance abuse, and migration are affecting these communities. The organization sees a lot of single-parent families. It is very likely then that children with disabilities would be part of this changing ecosystem and be affected by it.

Poverty continues to disproportionately impact children with disabilities. In a household with multiple children, parents often prioritize children without disabilities over the one with a disability. Families depending on daily wage earning are unable to devote time to the certification process which requires multiple hospital visits, as it means losing income. Lack of basic documentation is a big barrier. Deep rooted stigma and stereotype also play a role in dehumanizing children with disabilities and leads to a perception that there is little point in investing in a child who will never grow up and earn.

In conversations with one CWC, the CAFT-India team learnt that children with disabilities come into CCIs mostly through abandonment, usually at ages above 10 years. This could be because parents and families either do not have access to early interventions and rehabilitation, or they may not even know that the child has a disability till they reach a certain age. At that point, caring for the child becomes difficult without the support or knowledge needed by the caregivers. CWCs make efforts to avoid institutionalization to the extent possible. But their decisions are informed by their understanding of disability. For instance, the Chairperson of one CWC shared that for children with disabilities whose "level" allows them to live in the community and attend schools, the CWC supports linkage to reasonable accommodation for the child. There are also instances where students without disabilities support students with disabilities in the school. However, if the child's disability is perceived as being "disruptive" towards the "normal" activities and functioning of the school and peers, then the child is considered for referral to a CCI.

> ***It is important to note here that any child who behaves differently from others is seen as disruptive and can be sent to a hospital or a CCI. The prevailing view is that this behavior is inherent in the child and there seems to be very little effort to understand what is happening to the child. Behavior modification methods have come out of this thinking often leading to the use of methods that contravene the human rights and dignity of the child.***

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[x] Keystone Human Services International and the Children and Families Together – India program do not endorse these views. The findings from the interviews and meetings are being outlined in this section as shared by CWC members.

While there are individual variations in knowledge and understanding within the CWC, there are also no guidelines on how to work with children with disabilities that they could follow. With the JJ Act 2016, and its amended Rules not reflecting a unified understanding about children with disabilities, it is important that there be guidelines and standards on how they are to be treated in the system.

The CWCs that have been functional since 2022 had not received any training with regard to children with disabilities. In meetings with the CAFT-India team, members expressed interest to learn more about children with disabilities. This commitment to increase their understanding of disability is an opportunity for civil society organizations.

State of the CCIs

In discussions with Child Welfare Committees (CWCs), District Child Protection Unit (DCPU) and meetings with officials of Child Care Institutions (CCIs), the CAFT-India team learnt that staff in the CCIs are not trained to work with children with disabilities and nor do they seem to have access to any specialists who can guide them. This holds true also for the specialized adoption agencies (SAA) which have to be in every district of the country according to Supreme Court order.

The majority of children with disabilities in the CCIs do not go to school outside the premises. In fact, at one institution the team was told that children do not go out at all except to go for a CWC appearance or to the doctors. When asked if the children ever went for outings, the team was told that they were worried that children would run away if they were taken out for an outing. Children with disabilities in such closed-door institutions are likely to have or develop grave mental health difficulties and potentially difficulties in aftercare situations.

At another CCI, the team learnt that they had not seen any children with disabilities surviving till the age of 18. Therefore, there has not been much attention paid to aftercare plans for children with disabilities. Family members, including extended family, are reluctant to have their children who have disabilities live with them due to economic conditions. Older children without disabilities are taught skills on campus as electricians, etc. but there is no formal training.

There is a lack of a mechanism for doctor visits and therapeutic services, and it seems to be on an ad hoc basis. There is no linkage with either general government services or schemes available for children or those specialized for children with disabilities. In one CCI, the team found that not much effort has gone into accessing disability certification for children with disabilities.

It was also seen that many children with vision and hearing impairment do not get to become independent and live in the community. The CWCs shared with the team that children with hearing impairment and vision impairment seem to be going from one CCI to another when they come of age.

Sponsorship and other Alternate Care

As regards alternative care, the district of Gumla has done very well on sponsorship. Over 650 children have been given sponsorship in the district and sometimes there are more than two children in one family availing this. The guidelines have now changed and only two children from a family can get sponsorship. When it comes to disability, there are some barriers that exist to access sponsorship. For example, a child with a disability cannot get sponsorship if they do not have a disability certificate.

Often children living with grandparents do not have adequate identity papers. There is a need for much more awareness on certification and facilitation for children to get this very important identification. With the numbers of certification being low in the state, there is a need to address this at the level of the state government.

Another barrier to sponsorships for children with disabilities as shared by child protection functionaries, is the condition that they must attend school. For children with disabilities this is often a difficult condition to fulfil. However, a closer reading of the guidelines of Mission Vatsalya tells us that there can be an exemption for children with disabilities on this point.

The CWC also shared that a child can get both the disability pension and the scholarship simultaneously. One of the challenges that they are currently facing is that the state has not released the money for sponsorship for some months and therefore many children who are enrolled in sponsorship are not getting the benefit of it. The late release of funds is an ongoing issue.

According to the CWC there are no services or special educators for children with disabilities in schools. For deaf children there is a residential school in Gumla, but parents do not always want to part with their children. The department looking at education is different from the one under which the CWC lies and there are gaps in convergence. CWC members shared that the direction for convergence has to come from the state government.

There has been a lot of proactive outreach and information sharing in the districts on sponsorship (most people refer to it as scholarship) so many parents are approaching the CWC and DCPU and others.

A sentiment shared by the CWCs was the challenges that come from the lack of data. They requested support to address this as with proper data they can ask for more support for children with disabilities.

Reintegration

One of the major barriers in reintegration of children with disabilities is that sometimes children are unable to provide details of who their families are and where they come from. The CCI puts 'unknown guardian' against the names of these childen. This is a huge issue in the reintegration process and has been brought to the notice of the CWC.

Foster care and adoption is not common in a rural areas such as Gumla. Less than half of the total districts in Jharkhand have SAAs. This can become a big barrier in alternate care of children with disabilities.

Experiences from the ground

Deepshikha, one of the leading civil society organizations in Jharkhand working on disability, highlighted the importance of early intervention in their discussions with the CAFT-India team. However, their experience showed that there is a need to focus on sustainability. They felt Anganwadi workers still have limited knowledge on how to include children with disabilities in their work. The organization also shared experience of working with nutrition centers in the community to include children with disabilities. They shared that some of their services like the Cluster Resource Centre in Ranchi were working very well. They have started training teachers and other personnel, and assistive devices could be accessed from there once the child has a disability certificate. Many resource teachers in Jharkhand have been trained by Deepshikha and they can be a source of information in the districts where they are now working.

CONCLUSION

India has demonstrated concrete commitment to child protection, care reform and disability inclusion. The progressive laws and policies that have been adopted in the past few years are an indication of this commitment. Active steps are being undertaken to translate them on the ground. However, these changes must reflect the paradigm shift envisioned in the CRPD and the Rights of Persons with Disabilities Act 2016. There is a need for greater effort to translate this shift into support and services for children with disabilities and their families. Some of the ways in which this could be advanced include:

- Recognizing that children with disabilities are children first, and that laws that protect all children must also include children with disabilities.
- Bringing stronger convergence between the child protection laws and the disability laws, in particular the JJ Act machinery needs to align with the RPwD Act.
- Support services to strengthen communities must be prioritized, including early identification and intervention.
- Collecting reliable and comparable data disaggregated by disability.

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