

Alternative Report on India to the CRC Committee on the Rights of Children with Disabilities

Introduction

This joint submission provides supplementary information from the Indian disability movement to the third and fourth periodic reports submitted by the Indian government to the Committee on the Rights of the Child in 2011.

India ratified the UN Convention on the Rights of Persons with Disabilities (CRPD) and its Optional Protocol on 1 October 2007. It is clear that the human rights standards of the CRPD and the CRC intersect and reinforce each other when it comes to the rights of children with disabilities. While both the CRC and CRPD have made specific mention of the rights of children with disabilities, they continue to be amongst the most marginalised in India.

The present submission will touch upon the following issues:

- the failure to mainstream the rights of children with disabilities (pg 4);
- the lack of quality and reach of rehabilitation services (pg 7);
- the barriers to inclusive education (pg 9);
- the lack of protection for children with disabilities within the Juvenile Justice system (pg 12); and
- the extreme vulnerability of children with disabilities in areas affected by armed conflict (pg 16).

Suggested questions for consideration by the Committee for the List of Issues are regrouped at the beginning of this document and also figure at the end of each corresponding section throughout the text. Appendix 2 provides more information about the organisations jointly making this submission (pg 19).

Proposed Questions for Consideration under their respective List Of Issues –

The Failure to mainstream Rights (Articles 2, 3, 4, 8, 23) (See page 4 for details)

- What steps has the government taken to ensure reliable and correct estimates of numbers of children with disabilities within the country?
- What steps is the government taking to ensure that the identity and dignity of the child is clear and not subject to confusion within the country?
- What steps has the government taken to eradicate the continued discrimination on the basis of disability that children continue to face in India?
- Has the state party taken adequate steps to clarify responsibility and accountability of different Ministries for the fulfillment of the rights of children with disabilities?
- What steps is the government taking to include children with disabilities in all its programs for all children in a manner that is consistent with the rights laid out in the Convention on the Rights of Children with Disabilities (CRC)?

The Lack of Quality and Reach of Rehabilitation Services (Article 2, 3, 4, 23) (See page 7 for details)

- What steps are being taken to collect disaggregated data on children with disabilities and to reflect their needs in the planning and reporting of rehabilitation services for people with disabilities? In the absence of child specific data of rehabilitation services for people with disabilities, how is planning relating to children done?
- What steps are being taken to develop an action plan to reach out to every child with disabilities with services that will enable their full participation in society? How will disabled peoples' organisations and children with disabilities be consulted and actively participate in the development, implementation and monitoring of such a plan?

The Barriers to Inclusive Education (Articles 2, 3, 23, 28, 29,) (See page 9 for details)

- What reliable data is available on the enrollment, retention and dropout of children with disabilities in the country?
- In the absence of reliable data, how are planning & programming relating to children with disabilities done?
- What steps are being taken to ensure that the education of children with disabilities is centralised within and coordinated by the Ministry of Human Resources Development which covers the education of all children in India?
- What measures are being taken to ensure that mainstream schools are accessible to children with disabilities (e.g. physical environment, teacher training, curricula development, etc)?
- What steps have been taken to include inclusive education as an integral part of core teacher training curricula in universities to ensure that the values and principles of inclusive education are infused at the outset of teacher training and teaching careers of all teachers? And to ensure the accessibility of educational materials, curricula, and school environments, and for the law to provide enforceable remedies to children with disabilities and their families who have been refused access to inclusive education, or who have been denied the provision of reasonable accommodation with respect to education.

The lack of Protection of Children with Disabilities within the Juvenile Justice System (Articles 2,3,4,18,19,20,23,24,25,28, 34,37,39) (See page 12 for details)

- How is information about seeking help and making complaints against perpetrators made available to children with disabilities regarding violence, exploitation, or harmful practices both in the community and in institutions?
- What steps have been taken to address the heightened risk for children with disabilities of becoming victims of violence, abuse, exploitation and harmful practices in the home, institutions and the community?
- What measures are being adopted to ensure that both services (including shelters) and information for victims are made accessible to women and girls with disabilities?
- What are the steps taken by the State to deal with the human rights violations taking place within shelter homes designed to protect children with disabilities?
- Please provide information on the number of cases lodged alleging disability-based discrimination and hate violence against children with disabilities in the last years and their outcomes, including sanctions which were ordered against both public and private bodies or individuals in these cases.
- What are the steps taken by the state to provide supports to families (in terms of social security, information and rehabilitation services access to education and others) to ensure that the child with disability continues lives within their family and community?
- What steps has the state taken to ensure the participation of children and persons with disabilities and disabled people's organisations in the formulation of laws, policies, programs and guidelines that affect the rights of the child?

- What steps has the State taken to promote in-country adoption of children with disabilities?

The Extreme Vulnerability of Children with Disabilities In Areas Affected By Armed Conflict (Articles 2, 3, 23, 24, 32, 26, 36, 37) (See page 16 for details)

- Are there any statistics available as to how armed conflict has affected children including children with disabilities in India? What measures has the government taken to eliminate abuse and violation and ensure care and protection of all children including children with disabilities living in the areas affected by armed conflict?
- What efforts are being made to provide a legal and protective framework for development, education and protection of children with disabilities in Jammu and Kashmir?

Overview

In 2012, India took stock of twenty years of its ratification of the Convention on the Rights of the Child. **Article 23** of the CRC focuses specifically on the rights of the child with disabilities. In 2007, India ratified the UN Convention on the Rights of Persons with Disabilities. This Convention underlines the importance of focusing on the rights of children with disabilities with the General Principles of the Convention (**Article 3**) underlining the evolving capacities of children with disabilities and their right to an identity; a separate article (**Article 7**) entitled 'Children with Disabilities' reiterating that children with disabilities enjoy all human rights on an equal basis with others and many other articles throughout the Convention focusing on the rights of the child.¹ The UNCRPD reflects a big change in the thinking about disability rights.

Since its ratification the Indian government has initiated the process of amending and formulating new laws in place of the earlier disability laws². People with disabilities in the Indian disability movement have surged forward and actively engaged with government and put forth their proposals for change in law and policy.

In its policies, India has long acknowledged the vulnerability of children with disabilities and the need for specific action for them. In the Tenth Plan³ document India has specifically recognized children with disabilities as children living in difficult circumstances. In 2006, the *National Policy For Persons with Disabilities*⁴ made a special mention of children with a focus on the girls with disabilities. The 11th plan document focused on inclusion and one of its major aims was for "reservation of 3% allocation for persons with disabilities in all relevant Ministries, along with the formulation of clear guidelines and monitoring mechanisms"⁵ The recently announced National Policy For Children (2013)⁶ makes specific reference to the rights of children with disabilities.

Laws relating to children are beginning to acknowledge the extreme vulnerability of children with disabilities and acknowledge that the fulfillment of the rights of this child will require some specific action. However, despite this recognition, ***centuries of segregation and an overly medical notion of disability have left policy makers uneasy about how to define the rights of children with disabilities and to decide what is in the best interest of this child. Often specific reference to children with disabilities in law and schemes go against the underlying values enshrined in the CRC that India has long since ratified.***

Policy and legal intentions have not translated into practice or implementation. The gap between policy intentions and actual practice is so wide that it is difficult to see how India will bridge

¹ Article 16, 18, 23, 25, 30 of UNCRPD- <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>

² There are four disability specific laws in the country. The Persons with Disabilities (Equal Opportunities, Protection Of Rights And Full Participation) Act, 1995, The National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999, The Mental Health Act 1987 and the Rehabilitation Council of India Act 1992

³ http://wcd.nic.in/crc3n4/crc3n4_1r.pdf (Section 2.11.143, Page 268, 10th Five Year Plan, 2002-2007, Volume II)

⁴ http://www.svayam.com/pdf/English-national_disability_policy.pdf

⁵ http://planningcommission.nic.in/plans/planrel/fiveyr/11th/11_v1/11th_voll.pdf (Section 6.180., Pg. 131., 11th Five year Plan, 2007-12, Volume I)

⁶ <http://wcd.nic.in/childreport/npc2013dtd29042013.pdf>

this without focused attention, a different understanding of what is in the best interest of children with disabilities and a much larger commitment of resources.

Failure to Mainstream the Rights of Children with Disabilities (Articles 2, 3, 4, 8, 23)

India's uneasiness about children with disabilities is reflected in different approach taken by various sectors of the government towards children with disabilities. The Ministry of Human Resource Development addresses children with disabilities as 'children with special needs' (CWSN), while the Ministry of Social Justice and Empowerment addresses the same children as 'children with disabilities'. Other documents and guidelines use the word children with special needs to address a wide range of children including the child with disabilities.⁷ This confusion is reflected in India's official report to the CRC. The 3rd and 4th State report uses the terms 'differently-abled'⁸ 'children with disabilities'⁹ and 'children with special needs'¹⁰ to address the same set of children. This lack of consistency in addressing a set of children is not only discriminatory but also adds to the confusion about the identity of this child in the country.

Linked to this is the *continuing lack of understanding in the country as to the numbers of children with disabilities. The 3rd and 4th State report acknowledges this confusion and goes on to say "there are between 6 and 30 million children with disabilities in India, who have special needs"*¹¹. Surely such a wide variance in estimates cannot be the basis of any effective policy or program to improve the situation and respect for the rights of children with disabilities as the report goes on to suggest.

A wide disparity in the rights that are enjoyed by children with disabilities and other children is reflected in a deep exclusion and invisibility of children with disabilities in all programs for children. This is because the rights of children with disabilities are divided across different Ministries with none taking complete responsibility. This confusion and lack of ownership has resulted in the exclusion and isolation of children with disabilities from the mainstream. Children with disabilities continue to fall through the cracks of protection and support in India.

The Nodal Ministry for children and persons with disabilities is the Ministry of Social Justice and Empowerment (MSJE). This Ministry has generic programs for the 'empowerment of persons with disabilities' but hardly any program or scheme that has been designed keeping the rights and specific requirements of the child in focus. The responsibility for the education of children with disabilities continues to be divided amongst the Ministry of Social Justice and Empowerment and the Ministry of Human Resource Development (MHRD)¹², with neither taking full responsibility nor coordinating for the full participation in education for children with disabilities.

This situation continues despite the continuous demand by Disabled People's Organizations (DPOs) for full responsibility to be taken by the Ministry of Human Resource Development that deals with education, suggestions made by committees¹³, and the enactment of the Right of Children to Free and Compulsory Education Act 2009.

Furthermore, there is an absence of direct consultation with children with disabilities to find out what are their wishes and needs to better inform the development of laws, policies and programmes. Children with disabilities are hindered from participating themselves in these

⁷ http://www.adoptionindia.nic.in/guide_inter_country.htm

⁸ Preface, Point 5, Link - http://wed.nic.in/crc3n4/crc3n4_1r.pdf

⁹ Page 60, Link - http://wed.nic.in/crc3n4/crc3n4_1r.pdf

¹⁰ Page 18, Link - http://wed.nic.in/crc3n4/crc3n4_1r.pdf

¹¹ Page 49, Section 3B.3.1, Link - http://wed.nic.in/crc3n4/crc3n4_1r.pdf

¹² Ministry of Human Resource Development is the nodal Ministry for education of all children

¹³ Section 5.2, Recommendations made by the Committee drafting the Rights of Persons with Disabilities Bill, 2011, Pg. 9, <http://socialjustice.nic.in/pdf/report-pwd.pdf>

processes through the lack of age appropriate and disability appropriate supports which acts as a barrier to the expression of their views on an equal basis with other children.

For years children with disabilities have continued to be invisible in all programs and schemes created for all children. The Ministry of Women and Child Development designs and implements countrywide flagship programs for all children. Children with disabilities continue to be excluded in the very design of these schemes and in the reporting of the implementation of the schemes.

For example, the Integrated Child Development Scheme (ICDS) is the only major countrywide scheme for early childhood care and development. With its mandate for the provision of essential services of immunization, health check-up, and referral services, pre-school non-formal education and the provision of supplementary nutrition, “it is bringing early childhood care and education as an integrated package to all children.” It is also seen as the government’s major scheme to fight childhood malnutrition¹⁴. In 2001, while deliberating on the Right to Food case the Supreme Court of India declared the Integrated Child Development scheme to be a **legal entitlement of children of India in the 0-6 age group**. It has given orders for the universalization of the Integrated Child Development Scheme¹⁵. Through its 1.4 million anganwadi centres and its two million anganwadi workers and helpers, this scheme reaches out to “eighty six million children and their mothers through supplementary nutritional support and thirty three million children with pre-school education”¹⁶.

Unfortunately, this extremely important scheme that is supposed to give children a head-start in life and is also seen the government’s major scheme to fight childhood malnutrition, **is not designed to include children with disabilities in all its activities**. The only specific directions in the guidelines of this scheme is for the anganwadi worker to conduct a survey of children with disabilities in the community and to refer the child with disabilities to the nearest Public health Centre (PHC). While the scheme converges with many other Ministries such as health and human resource development to provide services to children, it does not converge with the Ministry of Social Justice and Empowerment (MSJE) to provide early intervention services to children with disabilities at a time when they need it the most. India’s latest report to the CRC Committee presents the ICDS in terms of **the prevention of disability**. It does **not report on the inclusion of children with disabilities in the scheme**¹⁷.

While the Ministry of Women and Child Development (MWCD) does not report on the inclusion of children with disabilities, families of children with disabilities and consecutive reports of the Supreme Court Commissioners on the right to food give alarming statistics and experiences of exclusion¹⁸.

The underlying causes of exclusion lie in lack of care, lack of knowledge, no convergence with habilitation and rehabilitation services, a lack of provisioning for the child with disabilities, discrimination and social exclusion often on the basis of disability. Finally a lack of reporting on children wipes out any traces of children with disabilities in implementation and planning¹⁹. In response to a Right To Information (RTI) query filed in October 2011 by the National Centre for Promotion of Employment for Disabled People (NCPEDP), the

¹⁴ Pg 38, Section 3.1.3, Point (a), Report of the Working Group on Child Rights for the 12th Five Year Plan (2012-17), Link -

http://planningcommission.nic.in/aboutus/committee/wrkgrp12/wcd/wgrep_child.pdf & Link for ICDS - <http://wcd.nic.in/icds.htm>

¹⁵ Jaishankar & Drèze, SC Orders On The Right To Food - A Tool For Action, 2005, Order dated 28th of November, 2001, Page 19) Link - <http://www.righttofoodindia.org/data/scordersprimeratoolforaction.pdf>

¹⁶ Section 6C.3.2, Pg. 135, Point No. 100, 3rd and 4th State CRC Report, Link - http://wcd.nic.in/crc3n4/crc3n4_1r.pdf

¹⁷ See point 26 Page 118, Link - http://wcd.nic.in/crc3n4/crc3n4_1r.pdf

¹⁸ See Page 44, 8th Report Of the Commissioners of the Supreme Court - September 2008 and also see Harsh Mander and M. Kumaran (2006) **SOCIAL EXCLUSION IN ICDS: A sociological whodunit?** (Link - http://www.righttofoodindia.org/icds/icds_surveys.html) See also section on Disability in State Survey Reports here - http://www.righttofoodindia.org/comrs/state_survey_reports.html

¹⁹ See page 8, Report of Jan Sunvai on Inclusive Education in South Delhi, AARTH-ASTHA in collaboration with Delhi Commission for Protection of Child Rights

Ministry of Women and Child Development has mentioned that The existing MIS (Management Information Systems) “does not capture information of disabled children”²⁰.

The consequences for children with disabilities are huge. ***It is impossible and not advisable for a country such as India to build a parallel system of early intervention for children with disabilities. Schemes for all children must include children with disabilities and be flexible enough to cater to their specific requirements or special needs.***

Articles 2,3,23,27,6

It is important to look at the cumulative impact of exclusion on the fulfillment of the rights of children with disabilities. In the specific context of India for example the right to food gains utmost importance. It is officially acknowledged that almost half of children under 5 years of age (48%) are vulnerable to growth stunts, 43% are underweight and 24% are severely undernourished²¹. Given this grave situation, as a direct measure, the government has undertaken to provide hot cooked meals to children in the 0 to 6 age group through its vast network of anganwadis in the ICDS scheme and to the growing number of school going children through the National Programme of Nutritional Support to Primary Education (NP-NSPE) popularly known as the mid-day meal scheme²². Both schemes have been declared as legal entitlements of all children by the Supreme Court of India²³

Yet both exclude children with disabilities in the way that they are designed and implemented. While we have already written of the ICDS, the midday meal scheme has been hailed as one of the most successful schemes of the government of India, with the supply of a hot cooked meal increasing enrolment and retention in schools and most importantly aiding social inclusion with children from different religions, castes and backgrounds eating together. Through its various orders over the years, the Supreme Court of India has expanded the reach of this scheme²⁴. However, the scheme has not been expanded to reach out to children with disabilities in special schools, in home based education and the very large numbers who are out of school. Children with disabilities in school often report that they have either not received the support to collect their meals or to eat their meals or they have to completely depend on their classmates to access their mid day meal²⁵. Therefore in a country where malnutrition is a “national shame”, the majority of children with disabilities are deprived of any supplementary nutrition when they are very young or of school going age thereby compromising their right to life, their development and ability to participate in society and community.

At the moment India is reworking many of these large important programs for all children. However, there has been no participation of disabled people’s organizations or participation of children with disabilities in processes for children.

- What steps has the government taken to ensure reliable and correct estimates of numbers of children with disabilities within the country?
- What steps is the government taking to ensure that the identity and dignity of the child is clear and not subject to confusion within the country?
- What steps has the government taken to eradicate the continued discrimination on the basis of disability that children continue to face in India?

²⁰ See Page 189, UNCRPD Key Issues in India Prepared by DEOC for NCPEDP, December 2011

²¹ Section 6C.1.3 , Point No. 46, Page 123, 3rd and 4th State CRC Report, Link - http://wcd.nic.in/crc3n4/crc3n4_1r.pdf

²² Point No. 6, Preface, 3rd and 4th State CRC Report, Link - http://wcd.nic.in/crc3n4/crc3n4_1r.pdf

²³ Jaishankar & Drèze, Orders related to Midday Meal, SC Orders On The Right To Food - A Tool For Action, 2005, Pages 16-18) Link - <http://www.righttofoodindia.org/data/scordersprimeratoolforaction.pdf>

²⁴ Chapter 2, Nutrition, Working Group Report On Elementary Education And Literacy 12th Five Year Plan 2012-2017, Link - http://planningcommission.nic.in/aboutus/committee/wrkggrp12/hrd/wg_elementary1708.pdf

²⁵ See Chapter III, Children Who Are Attending School, Third Annual Report on the Status of Children with disabilities Under The Right to Education Act, AARTH-ASTHA in collaboration with AAINA and SPARC-INDIA

- Has the state party taken adequate steps to clarify responsibility and accountability of different Ministries for the fulfillment of the rights of children with disabilities?
- What steps is the government taking to include children with disabilities in all its programs for all children in a manner that is consistent with the rights laid out in the Convention on the Rights of Children with Disabilities (CRC)?

The Lack of Quality and Reach of Rehabilitation Services (Article 2, 3, 4, 23)

There are a range of schemes and programmes for the rehabilitation of people with disabilities that are directed through legislation²⁶. A closer look will show us how they affect children with disabilities -

No Specific Focus on Children – There are a number of schemes and services meant specifically for people with disabilities. However, we do not see any evidence of a child rights framework in the design of any of these schemes. There has been no attempt to ensure the holistic development of the child through access to a range of services. Some schemes that are specially designed for children like *The Aspiration Early Intervention Scheme*²⁷ of the National Trust have only operated on a very small scale with only 79 centres reaching out to 1500 children with disabilities. Large schemes like *The Deendayal Disabled Rehabilitation Scheme*²⁸ – that cover everything from early intervention to vocational rehabilitation to special education to the district disability rehabilitation centres to community based rehabilitation, are not designed from the child rights perspective and therefore are not being able to steer their programs in the interest of the child. Schemes meant for all persons with disabilities do not report on the child with disabilities, making the child invisible in programming and reporting.

Reach of Services –The population of children with disabilities is officially about 6 to 30 million²⁹. Yet, **rehabilitation services have not reached more than 0.50 million (5 lakhs) people³⁰ which implies that far less than 8%³¹ of children with disabilities have accessed services.**

Some other services seemed to have gradually become less accessible over a period of time. For instance, during the introduction of the Niramaya Health Insurance Scheme of the National Trust, it had a cashless facility. In cases where the people don't have the resources to pay for medical services, the cashless facility of the scheme that made quality medical services available to people without paying for them, came as a great relief. This made Niramaya a scheme of great demand and huge number of people applied for it. But now the cashless facility is stopped and medical expenses have to be first borne by the client, which, after a complicated procedure, are reimbursed. As the people have to first pay for the services, the demand decreased. In other words, the scheme has been made inaccessible. The inaccessibility of the scheme is evident in the fact that it has only **107761** persons enrolled, many of whom have not renewed their policies leaving only **62821** active members at the close of the year 2011-12, out of which, insurance claims of **2907** people were settled in the year. Furthermore, most claims came from 3-4 states in a country of 28

²⁶ The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995, Link - http://bhind.nic.in/Sparsh_disability%20act%201995.pdf ; The National Trust For Welfare Of Persons With Autism, Cerebral Palsy, Mental Retardation And Multiple Disabilities Act, 1999, Link - <http://www.nimhindia.org/THE%20NATIONAL%20trust.pdf> ; The Rehabilitation Council of India Act, 1992, Link - http://www.svayam.com/pdf/the_rci_act-1992&amendment_act_2000.pdf ; and The Mental Health Act, 1987, Link - http://www.svayam.com/pdf/the_mental_health_act-1987.pdf under various Ministries. The nodal Ministry is the Ministry of Social Justice and Empowerment.

²⁷ See *Aspiration Early Intervention Scheme*, Link -

http://www.thenationaltrust.co.in/nt/index.php?option=com_content&task=view&id=110&Itemid=167

²⁸ See Deendayal Disabled Rehabilitation Scheme, Link - <http://socialjustice.nic.in/ddrs.php?pageid=2>

²⁹ Section 3B.3.1, Page 49, 3rd and 4th State CRC Report, 2011, Link - http://wcd.nic.in/crc3n4/crc3n4_1r.pdf

³⁰ Section 6B.6, Pont No. 32, Table 6.1, Page 120, 3rd and 4th State CRC Report, 2011, Link - http://wcd.nic.in/crc3n4/crc3n4_1r.pdf

³¹ Even if we take the population of children with disabilities as 6 million, the services reach to far less than 8% of children with disabilities, provided that in the absence of child specific data regarding reach of services, we have used the figure 0.50 million that implies all people with disabilities who have accessed services

states and 7 Union Territories³². The National Trust does not report on the number of children with disabilities who have been benefitted from this scheme.

Quality of services – Quality of services has a direct implication to the quality of life of people with disabilities. The reach of the rehabilitation services have already given us a glimpse of the quality of services. Our experience in the field has shown that the services suffer from accessibility issues due to complicated procedures, low quality, irregularities in delivery and associated factors. For instance, In the name of social security, the central government allows a negligent amount of Rs. 300 (around 5 USD). Though some states add to the amount provided by the central Government from state fund, most states don't. Furthermore, evidences about poor quality of service under schemes are overwhelming – for instance, that aids and appliances provided under the ADIP Scheme are not of standard quality. Their life span is very short and hence after a brief period of use of an aid, it becomes dysfunctional leaving the child dependent on others³³. It has also been seen that distribution of aids and appliances without delivering the required training of how to use it or the information of where to get them repaired has not helped children with disabilities. *Pratidhwani*, a parents organization for children with hearing disability demanded to the Department of Disability Affairs, Ministry of Social Justice and Empowerment, that hearing aids must be provided on a non-profit basis through the ADIP Scheme³⁴ with provision of providing battery and ear mould for the aids for minimum of three years and accessible repairing facilities and training should be provided to parents and guardians on the importance, use and maintenance of hearing aids³⁵. The availability of aids and assistive devices is crucial for independent living and personal mobility of children or persons with disabilities. Such services have to be designed keeping in mind the requirements of children, of women and girls with disabilities and of the varied environments in which children and persons with disabilities live in India. Yet, the *ADIP Scheme* reaches only around 0.25 million (2.5 lakhs)³⁶ persons with disabilities annually which is a negligent number for a scheme that has the responsibility of providing aids and assistive devices to more than 60 million people with disabilities³⁷ including 6-30 million children with disabilities. *Further, there are huge gaps in ensuring the right to these services particularly among the children with disabilities residing in rural India as most of the services are housed in urban India*³⁸.

Disability Certificate: An Important Document to Avail Services & Entitlements – It must also be brought to light that to access most of these schemes, a child requires a disability certificate that is issued by a medical board after examination. It was assured by the Health Ministry that by the end of the Eleventh Plan, every disabled person will have a disability certificate³⁹. ***However, the reality is that only 35% of the people with disabilities in India possessed disability certificates till February, 2010***⁴⁰. ***Again, disaggregated data for children relating to disability certificates is not available.*** One of the obvious reasons why such a small population has disability certificate is the fact that the process for getting a disability certificate issued is very complicated. Lack of certain documents creates procedural deadlocks making it particularly difficult for families that have migrated from one state to another and may not possess the residence and identity documents required for the certificate. During our experiences in the field we have encountered

³² See report of the JS and CEO & Page 50, Annual Report 2011-12, The National Trust, Link -

<http://www.thenationaltrust.co.in/nt/images/stories/Downloads/english%20annual%20report%202011-2012.pdf>

³³ Javed Ahmad Tak, Children with Disabilities in J&K, see Para 1, Information provided by Email

³⁴ See ADIP Scheme, Link - <http://socialjustice.nic.in/pdf/adipsch.pdf>

³⁵ See Point No. 2, Charter of Demands from Pratidhwani

³⁶ See Point No. (d), Page 135, Annual Report 2010-2011, MSJE, Link - <http://socialjustice.nic.in/pdf/ar11eng.pdf>

³⁷ It is acknowledged the population of people with disabilities in India can be reasonably assumed to be between 5-6% i.e. more than 60 million (in a country of 1.21 Billion people – Census 2011) See Section 6.172., Page 130, Eleventh Five Year Plan (2007–2012), Inclusive Growth, Volume I, Link - <http://planningcommission.nic.in/plans/planrel/fiveyr/welcome.html>

³⁸ See Para 2, Charter of Demands from Pratidhwani

³⁹ See Point No. (d), Page 40, Annual Report 2010-2011, MSJE, Link - <http://socialjustice.nic.in/pdf/ar11eng.pdf>

⁴⁰ Section 6.3, Page 122, Annual Report 2010-2011, MSJE, Link - <http://socialjustice.nic.in/pdf/ar11eng.pdf>

several instances where children had been given wrong certificates leading to a whole new set of problems including inability to avail the relevant services.

Children with disabilities who are within the Autism spectrum face huge discrimination as there is no officially acknowledged assessment tool to provide them with a certificate. The common practice is to provide the child with a certificate labelling them as 'Mentally Retarded'. Such discrimination has continued for years despite disabled people's organisation protesting and bringing it to the notice of the State⁴¹.

Lack of Trained Personnel – As per the data made available in the Annual Reports of the MSJE, the 7 National Institutes for disabilities that are responsible for training manpower in areas of disability training and rehabilitation annually produce slightly over 2000 trained personnel altogether. 2091 students were enrolled in the courses of the 7 Institutes altogether in 2010-11. Hence, the country faces a tremendous lack of trained manpower⁴².

Low Budgets and Underutilization of Resources - *The pattern of low budgetary allocation coupled with underutilization of resources has become endemic. Though the Eleventh Plan saw a rise of Rs. 733.86 Crores for disability as compared to the Tenth Plan allocation, the percentage of allocation to disability in the Eleventh plan was 15%, less than the 17% of the Tenth Plan.* Here we see that though there was a substantial increase in the budget, the relative allocation for persons with disabilities went down. There has been a pattern of underutilization of funds allocated for Disability under the MSJE. ***In the 10th Plan, Rs. 1166.14 Crores were allocated for Persons with disabilities, out of which Rs. 919.05 Crores or 79% of the amount was spent.*** ⁴³ ***If we look at individual years, the revised estimates for the session 2009-10 was Rs. 232 crores out of which Rs. 197.35 crores or 85.06% of the revised estimates were spent while in the next session 2010-11, the revised estimates was Rs. 374.34 crores out of which only Rs. 314.19 crores or 83.93% were spent***⁴⁴.

- What steps are being taken to collect disaggregated data on children with disabilities and to reflect their needs in the planning and reporting of rehabilitation services for people with disabilities? In the absence of child specific data of rehabilitation services for people with disabilities, how is planning relating to children done?
- What steps are being taken to develop an action plan to reach out to every child with disabilities with services that will enable their full participation in society? How will disabled peoples' organisations and children with disabilities be consulted and actively participate in the development, implementation and monitoring of such a plan?

The Barriers to Inclusive Education (Articles 2, 3, 23, 28, 29,)

The enactment of the Right of Children to Free and Compulsory Education Act, 2009⁴⁵ marked a historic moment for the children of India. While children with disabilities are part of all children in India, this historic Act is uneasy about how to include this set of children within the general education system. So while on the one hand all children with disabilities are covered by the Right to Education Act (RTE Act), it also invokes the Persons with Disabilities Act, 1995 when it mandates that children with disabilities shall have the *right to pursue free and compulsory elementary education*

⁴¹ See Letter titled 'Disability Certificate For Persons With Autism' Sent by Merry Barua, Action for Autism (www.autism-india.org) to Smt. Kumari Selja, Minister, MSJE & also see http://www.autism-india.org/afa_autisminindia.html

⁴² See Page 417, Annual Report 2010-2011, MSJE, Link - <http://socialjustice.nic.in/pdf/ar11eng.pdf>

⁴³ Total Allocation of MSJE during 10th Plan was Rs. 6976.93 Crores out of which Rs. 1166.14 Crores was allocated for People with Disabilities. In the 11th Plan, the figures were Rs. 13043 Crores and Rs. 1900 Crores respectively. See Table 4.1, Page 144, How Inclusive is the Eleventh Five Year Plan, People's Mid Term Appraisal

⁴⁴ See Table 2.2, Page 10, Annual Report 2010-2011, MSJE, Link - <http://socialjustice.nic.in/pdf/ar11eng.pdf>

⁴⁵ See Right to Education Act, 2010, Link - <http://www.delta.org.in/form/rte.pdf>

in accordance with the Chapter V of the said Act⁴⁶. Chapter V of the PWD Act legitimizes a whole range of educational options, including non formal options for children with disabilities. Through a recent amendment⁴⁷, children with disabilities have become a named category amongst the 'disadvantaged groups' in the Right to Education Act. In the same amendment, children with severe and multiple disabilities were offered the choice of 'home based education' as part of their right to free and compulsory education. At the level of implementation, the education of children with disabilities continues to be divided across the Ministry of Social Justice and Empowerment running special schools and the Ministry of Human Resource Development running the general education system with neither converging with the other.

This confusion on how the fundamental right to education of children with disabilities in India is to be fulfilled is not new to India. Unfortunately, its implications on the participation of children with disabilities in education can be seen in the very small numbers of children with disabilities within the education system and the tremendous barriers faced by those who are within the system. The confusion starts with the way we report on children with disabilities and the numbers that are projected by different official agencies. The Sarva Shiksha Abhiyan (SSA)⁴⁸, the flagship program of the government for the implementation of the RTE Act, has had a separate component on inclusive education focusing on education of children with disabilities within the general school system. However, even this focused approach has not lead to a significant inclusion of children with disabilities within the general education system.

According to the analytical tables on elementary education published by DISE in 2008-09⁴⁹, *the number of enrollment of children with disabilities has always remained about one percent of the total enrolment in the elementary classes.* However, if we look at the data, the enrollment has been less than one percent over a span of a decade⁵⁰. Despite the RTE and the commitment to free and compulsory education, the DISE shows us that the numbers of children with disabilities enrolled in the schools within the last five years has fallen drastically from **1554353 in 2007-08 to 1384166 in 2008-09**. The latest report of the RTE Forum⁵¹ states, "Lack of reliable data regarding the actual numbers of Children with Disability greatly hampers planning and provisioning for them".⁵²

In its march to universalize education, India has had focused strategies on children who are the hardest to reach and most vulnerable. However, there does not seem to have been a strong push to include children with disabilities. The study conducted by SRI-IMRB in 2009 shows that among school children belonging to disadvantaged categories including Girls, Scheduled Castes, Scheduled Tribes and Muslims the highest percentage of out of school children were children with disabilities with a staggering 34.12%. In the study conducted by SRI-IMRB in 2005, the percentage of out of school children with disabilities was 34.19%, which indicated that there was a decrease in number of out of school children with disabilities only by 0.7% in four (4) years.⁵³ Interviews with children and families of children who

⁴⁶ See Chapter V, The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995, Link - http://bhind.nic.in/Sparsh_disability%20act%201995.pdf

⁴⁷ See RTE Act, Amendment, 2012, Link - http://righttoeducation.in/sites/default/files/rte_amendment_act-2012.pdf

⁴⁸ See Sarva Shiksha Abhiyan (SSA), Link <http://ssa.nic.in/>

⁴⁹ See Analytical Tables 2008-09, District Information System for Education (DISE), Link -

<http://www.dise.in/Downloads/Publications/Publications%202008-09/AR%202008-09/Analytical%20Tables.pdf>

⁵⁰ See DISE Analytical Tables 2004-5 to 2011-12, Link - <http://www.dise.in/AR.htm>

⁵¹ Right to Education Forum (RTE Forum) is a platform of national education networks, teachers' unions, peoples' movements and prominent educationists with a combined strength of 10,000 NGOs from all over India, see <http://www.rteforumindia.org/>

⁵² See Page 34, Status of Implementation of the Right of Children to Free and Compulsory Education Act, 2009: Year Three (2012-13), A Draft Report by RTE Forum

⁵³ See Page 24, Working Group Report On Elementary Education And Literacy 12th Five Year Plan, 2012-2017, Link -

http://planningcommission.nic.in/aboutus/committee/wrkgrp12/hrd/wg_elementary1708.pdf & also see All India Survey of Out of School Children of Age 5 and 6-13 Years Age Group, Social and Rural Research Institute, Link - <http://www.educationforallindia.com/Survey-Report-of-%20out-of-school-children-IMRB-MHRD-EDCI-2009.pdf>, also see SRI-IMRB here - <http://www.imrbint.com/>

have never gone to school bring out a picture of grave distrust between families and the school system going far beyond obvious rejection. Families are unable to see how their children will be educated within the education system, given the way it is structured, ordered and implemented in our country. Despite the fundamental right to education, children with disabilities continue to be pushed out of the system and face tremendous discrimination on the basis of disability. This starts with denial of admission⁵⁴, lack of provision of transport and/ or escort allowance, making it extremely difficult for the child to enter the school⁵⁵.

Once within the school, children with disabilities are allowed to play a very limited role as the curricula, environment and attitudes of school staff have not been adapted to ensure their meaningful and practical inclusion. For instance, most children with disabilities are kept out of participating in extra-curricular activities such as games and cultural activities that are key to their all-round development. Infrastructural barriers limit the possibilities of active participation of children with disabilities in all activities within school. **The RTE Forum reported that *Physical barriers and transport facilities have been critical barriers for children with disabilities to fully access schooling as a large numbers of schools do not have barrier free infrastructure*⁵⁶. Linked to this is the strong feeling of parents that the school system as it stands today will not be able to take care of their child adequately. Lack of transport, no support staff who would care for their child, help them move, eat & study, and the fear that their child will not be looked after and would not be safe and secure in the school is foremost in the minds of most parents.** Most parents have expressed that teachers and staff are not aware and sensitive to the needs of children with disabilities, which has also been often reported by studies.⁵⁷⁵⁸ Furthermore, the gender gap in enrollment continues to be the widest among all children with disabilities. In comparison to the gender parity index of all children which is 0.94, children with disabilities stand very low at 0.76⁵⁹. Without proper guidance, support and an alternative way of looking at the education of children with disabilities, their successful inclusion and development remains challenged.

Similarly it has been observed that many children with disabilities drop-out from school due to a number of reasons ranging from lack of reasonable accommodation within schools, lack of transportation facilities, discrimination on the basis of disability, lack of proper guidance from teachers, denial to take responsibility of the child and lack of care and attention by school authorities. These are also some of the problems that came from the parents of children with disabilities. It has also been reported that as the disabilities of a number of children progressed to a more severe state, they had to drop out. Here, the schools were not seen making necessary arrangements for the education of these children. Parents have felt that the teachers, support staff and the school authorities are not aware about disabilities and sensitive towards the needs of children with disabilities. Children and parents alike have complained about the absence accessible and hygienic toilets, drinking water and lack of support⁶⁰. All these factors also create parental disinterest or lack of interest in children toward going to school, which may be a reason for dropping

⁵⁴ See case study of a petition - Shri Dinesh Kumar Chandak Vs. Union of India [W.P.(C) No. 4313/2012], Supreme Court of India, 2005, Provided by Shishu Sarothi (www.shishusarothi.org) by Email

⁵⁵ See Chapter VI, Children Who Have Never Set Foot in School, Third Annual Report on the Status of Children with disabilities Under The Right to Education Act, AARTH-ASTHA in collaboration with AAINA and SPARC-INDIA

⁵⁶ See Page 34, Status of Implementation of the Right of Children to Free and Compulsory Education Act, 2009: Year Three (2012-13), A Draft Report by RTE Forum

⁵⁷ See Chapter III, Children Who Are Attending School, Third Annual Report on the Status of Children with disabilities Under The Right to Education Act, AARTH-ASTHA in collaboration with AAINA and SPARC-INDIA

⁵⁸ See Table 40, Page 69, A Profile of Disability in Odisha – Trends, Development and Dynamics, WCD Dept., Govt. Of Odisha & Swabhiman

⁵⁹ See Figure 3.1, Page 105 for all children & Page 124 for Children with disabilities, Gender Parity Index, Enrollment Based Indicators, DISE data 2010-11, Link - <http://www.dise.in/Downloads/Publications/Publications%202008-09/AR%202008-09/Enrolment-Based%20Indicators.pdf>

⁶⁰ See All Chapters, especially Chapter IV, Children who have Dropped-Out of School, Third Annual Report on the Status of Children with disabilities Under The Right to Education Act, AARTH-ASTHA in collaboration with AAINA and SPARC-INDIA

out.⁶¹ **Unfortunately, the drop-out rates for children with disabilities are not maintained in the reporting of both SSA and DISE making it impossible to provide any figures⁶².**

- What reliable data is available on the enrollment, retention and dropout of children with disabilities in the country?
- In the absence of reliable data, how are planning & programming relating to children with disabilities done?
- What steps are being taken to ensure that the education of children with disabilities is centralised within and coordinated by the Ministry of Human Resources Development which covers the education of all children in India?
- What measures are being taken to ensure that mainstream schools are accessible to children with disabilities (e.g. physical environment, teacher training, curricula development, etc)?
- What steps have been taken to include inclusive education as an integral part of core teacher training curricula in universities to ensure that the values and principles of inclusive education are infused at the outset of teacher training and teaching careers of all teachers? And to ensure the accessibility of educational materials, curricula, and school environments, and for the law to provide enforceable remedies to children with disabilities and their families who have been refused access to inclusive education, or who have been denied the provision of reasonable accommodation with respect to education?

The lack of Protection of Children with Disabilities within the Juvenile Justice System (Articles 2,3,4,18,19,20,23,24,25,28, 34,37,39)

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,⁶³ 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.

In 2011, **section 58⁶⁴** of the JJ act was amended. This amendment allows 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 is undergoing change as a result of India's ratification of the UNCRPD and one that relies heavily on institutionalization of persons with disabilities underlines the strong belief still prevalent in India that institutionalization and medical care is the only way to rehabilitate children and persons living with mental illness.

The JJ Act works through an 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 the Child-lines (a countrywide help-line 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.⁶⁵ The

⁶¹ See Page No. 83, Teacher interventions for children with special needs, Challenges to Education in Jammu and Kashmir, Save the Children, 2011

⁶² Page 13, Second Annual Report on the Status of Children with disabilities Under The Right to Education Act, AARTH-ASTHA, Link - <http://www.rtemaharashtra.org/downloads/disabilityrep.pdf>

⁶³ See Section 2.1 of the JJ Act, Link - <http://wcd.nic.in/childprot/jjactamedment.pdf>

⁶⁴ Section 58 – Link - http://meghpol.nic.in/acts/central/juvenile_justice_care-protection_children_amendment_act_2011.pdf

⁶⁵ 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 Child-lines and the Child Welfare Committees in Delhi.

integrated child protection scheme (ICPS) that brings together all the government schemes and bodies working to implement the JJ Act was launched in the 11th plan, it is another flagship program of the government of India and is to be universalized throughout the country.

The ICPS makes specific reference to the child with disabilities only in the context of institutionalization. While recognizing that “poverty and lack of social security and medical services tend to cause parents to abandon children with physical and mental disability” the specific solution for this is to provide “specialized institutional care and treatment including medical, nutritional, and psychological support⁶⁶.

It is a matter of grave concern that specific recognition of high levels of abandonment has not resulted in either a detailed official study, policy directions or indeed strategies to secure the child within their family and communities so that children with disabilities can exercise their right to stay and be cared for within their family.

The deplorable conditions of shelter homes, observation homes and special homes for all children have been the focus of many debates in the media, civil society and government in recent years in India. However, because of the lack of inclusion, these debates rarely focus on children with disabilities.

The 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*.⁶⁷

The investigations into the horrific situations have largely taken place through Public interest Litigation by concerned individual as in the case of Asha Kiran (A residential home for intellectually disabled children and adults)⁶⁸ and some reports of civil society. Courts have also taken suo moto cognizance of news reports⁶⁹ and investigated the situation of homes for children particularly those with intellectual disabilities. These PILs and the consequent reports of different human rights Commissions, High Court Committees and disability rights organizations have brought into focus gross human rights violations against children and persons with disabilities.⁷⁰

Unusually high number of deaths with little or no investigation or accountability are cited on Reports. **Thirty five (35) children with intellectual disabilities died in two years in**

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.

⁶⁶ See sec 4.5, Titled Specialized Services for Children with Special Needs, Link - http://wcd.nic.in/icpsmon/st_abouticps.aspx

⁶⁷ See News Reports’ Links - <http://indiatoday.intoday.in/story/kerala-asylum-treats-mentally-ill-inmates-like-animals/1/167147.html>;
<http://www.thesundayindian.com/en/story/license-mandatory-for-private-mental-care-units-in-kerala/118/28243/>;
<http://www.deccanherald.com/content/228358/sordid-story-arya-anathalaya.html>;
http://articles.timesofindia.indiatimes.com/2012-07-13/kolkata/32663133_1_guriya-death-certificate-hooghly;
<http://www.hindustantimes.com/News-Feed/Chunk-HT-UI-No-Country-for-Children-2012-TopStories/Kids-at-Asha-Kiran-treated-like-animals/Article1-891567.aspx>;
http://articles.timesofindia.indiatimes.com/2011-03-12/mumbai/28683292_1_shelter-homes-asha-bajpai-mentally-deficient-children;
<http://www.indianexpress.com/news/rescued-orphanage-girls-to-be-rehabilitated-soon/895365/>;
<http://www.indianexpress.com/news/court-frames-charges-against-10-for-abusing-orphanage-inmates/898325/>;
http://articles.timesofindia.indiatimes.com/2012-04-07/lucknow/31304399_1_minor-girls-orphanage-childless-couple;
<http://www.indianexpress.com/news/haryana-cops-raped-us-childrens-home-inmates/958499/>;
<http://ibnlive.in.com/news/more-sexual-abuse-in-haryana-shelter-homes/265240-3.html>;
<http://ibnlive.in.com/news/naked-yoga-oral-sex-in-haryana-shelter-home/265947-3.html>;
http://articles.timesofindia.indiatimes.com/2012-07-04/chandigarh/32535930_1_rohtak-superintendent-shelter-home-hostel-warden;
<http://www.tribuneindia.com/2012/20120402/himachal.htm#10>;
<http://www.himvani.com/news/2012/07/18/open-letter-chief-secretary-order-request-judicial-inquiry-age-home-basantpur/20770>;
<http://www.thehindu.com/todays-paper/deafmute-girls-allegedly-raped-in-jaipur/article4728968.ece>;
<http://www.punemirror.in/article/4/2011050520110505062306773652f871f/Monsters-Shocking-evidence-of-brutal-assault-at-Panvel-shelter.html>

⁶⁸ Asha Kiran, founded in 1961, is located in Rohini, Delhi. The Asha Kiran complex is made up of six institutions for intellectually disabled persons. These include homes for intellectually disabled children - it is known to be the only such facility in northern India. Human rights violations have been reported from this group of institutions since the 1990s. In 2009, based on the violations of children and intellectually disabled adults in observation homes in Delhi and the high number of unexplained deaths in the Asha Kiran home, Reena banerjee filed a PIL before the High Court of Delhi and was later joined by Raj Hans Bansal, Chief Editor, Human Rights Observer.

⁶⁹ On August 23, 2010 Mumbai Mirror reported that five children had died of malnourishment in a home for children with intellectual disability in Maharashtra. Some were sexually abused and more would have died if they had not been shifted because of the report. The High Court of Mumbai took suo motu cognizance of this article and public interest litigation was initiated. The high Court appointed a Co-Ordination Committee for Child Protection with Dr Asha Bajpai Amicus Curiae (friend to the court) on this matter as the Chairperson. The committee visited 23 homes for children with intellectual disability throughout the state of Maharashtra and submitted a report on the situation in these homes.

⁷⁰ See Report on the Conditions of the Homes for Children with Disability Within West Bengal, 2006, Disability Activists Forum and also see Chauhan, Lost innocence!, Hindustan Times, Link - <http://www.hindustantimes.com/India-news/NewDelhi/Lost-innocence/Article1-346535.aspx>
 Chetan Chauhan, Hindustan Times (Chauhan, 2008)

Maharashtra. “The Home is not held responsible and there is no mechanism to ensure that the death was not due to preventable causes⁷¹. Thirty seven (37) children died in one home of the Asha Kiran Complex in Delhi over a period of four years (2004-2008)⁷². It has been reported that proper medical care and treatment could have saved many lives. Furthermore, Post-Mortem was avoided in most cases, which goes against the law of the land, as the concerned children were inmates living under government custody.⁷³

Medical negligence starvation and neglect, Sexual abuse situations of ill treatment and torture abound in these homes. Underlying these are structural issues, unbearable living conditions, lack of required records on children, untrained and underpaid staff, governance issues with the lack of oversight and willful negligence from personnel who are charged with protecting children in the system⁷⁴. 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 recreations and play and vocational training or skill building activities characterise the majority of homes that have been studied and visited in different states in the country. Instead “They live in the homes worse than prisoner for rest of their life doing nothing constructive. They become sort of free bonded labor of the home owners and been used practically for every purpose – some are being used as house maid to daily labor in field owned by the home owners or the club/society”.⁷⁵

Reports point to the large number of residents who enter homes (for children with mental disability) as children become adults but continue to live in the same way in the same home **often for the rest of their lives**. This even though many residents in these homes are capable of self care and independent living⁷⁶ The state has no plan in place for their growth and development and finally for their reintegration in society.

The lack of planning and forethought in setting up of shelter homes is evident in the unregulated mushrooming of residential facilities for children and persons with disabilities. This is linked with a laxity and corruption in the process of giving licences to people who have no knowledge and training to understand the needs of children with disabilities. The lack of shelter facilities for girls is another cause for concern. ⁷⁷ Similar situations are being reported with a mushrooming of private mental hospitals in the country which will now make institutionalisation increasingly easier⁷⁸.

⁷¹ Executive summary of status report of homes for mentally deficient children in Maharashtra, Author The Maharashtra State Coordination Committee for Child Protection appointed by the Bombay High Court, July 2011 pg 20

⁷² Report received in response to RTI enquiry vide letter no. 40/RTI/2/DD(FAS)/DSW/2008/8084 dated 10/08/08

⁷³ A Report on the Visit (1.02.2010) of Asha Kiran Complex, Delhi Commission for Protection of Child rights, Government of N.C.T of Delhi

⁷⁴ See Page 21-22, Executive Summary of Status Report of Homes for Mentally Deficient Children in Maharashtra, The Maharashtra State Coordination Committee for Child Protection appointed by the Bombay High Court, July 2011

⁷⁵ See Footnote 32 & Report on the Conditions of the Homes for Children with Disability Within West Bengal, 2006, Disability Activists Forum; See also Executive Summary of Status Report of Homes for Mentally Deficient Children in Maharashtra, The Maharashtra State Coordination Committee for Child Protection appointed by the Bombay High Court, July 2011; A Report on the Visit of Asha Kiran Complex, Delhi Commission for the Protection of Child Rights, 2010; A Monitoring Report on the Functioning of the Govt.-run- Home for Mentally Retarded persons (Including Children) in Asha Kiran Complex, Avantika, Delhi submitted by the National Commission for the Protection of Child Rights;

⁷⁶ (For example in Maharashtra, “according to data provided by Superintendents, 59% of the children in Homes across the state are capable of self-care and independent living.” - Executive Summary of Status Report of Homes for Mentally Deficient Children in Maharashtra, The Maharashtra State Coordination Committee for Child Protection appointed by the Bombay High Court, July 2011; Once children are sent to a home there is no plan to enable them to leave the home at the age of 18 and reintegrate into society. No plans are in place to relocate inmates into another facility when they reach adulthood. - Report on the Conditions of the Homes for Children with Disability Within West Bengal, 2006, Disability Activists Forum.

⁷⁷ Executive Summary of Status Report of Homes for Mentally Deficient Children in Maharashtra, The Maharashtra State Coordination Committee for Child Protection appointed by the Bombay High Court, July 2011, Page 14.

⁷⁸ Following a Supreme Court Order of 2002, and in reaction to great human rights violations which occurred within a private shelter in 2001, the government of India was placed under pressure to fully implement the Mental Health Act 1987 throughout the country. As compliance, the GOI liberalized norms for setting up private mental hospitals, and by 2009, despite the advent of the CRPD, over 400 private mental hospitals have sprung up in India, with applications continuing to go before the state mental health authorities.

What is a cause of grave concern is that the situation in some of these facilities has been highlighted over a period of many years by civil society and the government itself but the situation has not changed.

Of concern is also the fact that neither the nodal ministry for children and persons with disabilities (Ministry of Social Justice and Empowerment), the Commissioner for Persons With Disabilities, nor the nodal ministry for all children (the Ministry of Women and Child Development nor the National Commission for the Protection of Child Rights) have taken this up as an issue requiring urgent action, legal and policy interventions.

Alternative Care: foster Care and Sponsorship, Aftercare, Adoption (Articles 2, 3, 20, 21, 23)

Recent guidelines issued by the Ministry of Women and Child Development on Sponsorship and after care have not been made keeping the child with disabilities in mind. For example the guidelines on sponsorship aims at the “de- institutionalization of children who are in institutions and as a support to “families living in extreme conditions of deprivation or exploitation to enable the child to remain in his or her family”⁷⁹. The guidelines aims to do this by providing some money and enabling the child to attend school and the anganwadi.

The guidelines do not take into account the fulfillment of disability related needs and disability related expenses. Nowhere does the scheme talk about enabling the child with disabilities to access rehabilitation facilities, the disability certificate and the few entitlements that this child has. Without a specific mention of these, it is unlikely that parents living in extreme conditions of deprivation will be enabled to keep their children with disabilities. Considering the fact that the huge barriers the child with disabilities faces in accessing the education and the ICDS services it will be difficult for the parent to ensure the child’s enrollment and continued attendance as envisaged by the guidelines.

Similarly, the guidelines for aftercare⁸⁰ are not made with any understanding of supported living and the supports that some children with disabilities will require to live as independently once they have turned eighteen. As a result it is very likely that India will continue to see institutionalization as the only option for a child with disability in distress. Children with disabilities will enter homes and continue to live there for the rest of their lives in direct contravention of all the rights stated in the CRC.

Adoption

In June 2011 India formulated a new set of guidelines governing the adoption of children⁸¹. These guidelines clearly violate the CRC and the Hague Convention (Convention on Protection of Children and Co-Operations in Respect of Inter Country Adoption) with regard to the child with disabilities.

While the guidelines clarify that *(1) the best interest of the child is served by providing him or her an opportunity to be placed with a family within his or her own socio-cultural milieu in the country itself* (Section 8), this does not apply to the child with disabilities. A large number of children have been put under the category of children with special needs under these guidelines.⁸² Adoption for these children is to be fast tracked - *“completed as expeditiously as possible”*. ***For these children our guidelines have another standard. The ratio of 80:20 for in- country and inter- country adoption that is to be followed for all children is not to be followed for children with special needs.***⁸³ ***This implies that in the case of children with special needs, the rule of ensuring domestic adoption as***

⁷⁹ Guidelines For Sponsorship for Children under ICPS, Link - <http://wcd.nic.in/icpsmon/pdf/sponsorshipdtd24052012.pdf>

⁸⁰ Guidelines For After Care of Children under ICPS, Link - <http://wcd.nic.in/icpsmon/pdf/aftercare18042012.pdf>

⁸¹ Guidelines Governing the Adoption of Children, 2011, Link - http://adoptionindia.nic.in/guideline-family/new_guideline.html

⁸² Section 44, Guidelines Governing the Adoption of Children, 2011, Link - http://adoptionindia.nic.in/guideline-family/Part_I.pdf

⁸³ Section 9, Guidelines Governing the Adoption of Children, 2011, Link - http://adoptionindia.nic.in/guideline-family/Part_I.pdf

a first option does not apply. The relinquishment of many children who can otherwise be provided treatment and can continue to live with their biological family is thus promoted.” The guidelines merely require a certificate to be obtained from the medical board constituted by the government specifying the nature and percentage of disability in case foreigners are adopting children with special needs⁸⁴. The guidelines acknowledge that many children with special needs may not be adopted. Once again, the solution is that they “sent to specialized institutions.”⁸⁵

- How is information about seeking help and making complaints against perpetrators made available to children with disabilities regarding violence, exploitation, or harmful practices both in the community and in institutions?
- What steps have been taken to address the heightened risk for children with disabilities of becoming victims of violence, abuse, exploitation and harmful practices in the home, institutions and the community?
- What measures are being adopted to ensure that both services (including shelters) and information for victims are made accessible to women and girls with disabilities?
- What are the steps taken by the State to deal with the human rights violations taking place within shelter homes designed to protect children with disabilities?
- Please provide information on the number of cases lodged alleging disability-based discrimination and hate violence against children with disabilities in the last years and their outcomes, including sanctions which were ordered against both public and private bodies or individuals in these cases.
- What are the steps taken by the state to provide supports to families (in terms of social security, information and rehabilitation services access to education and others) to ensure that the child with disability continues lives within their family and community?
- What steps has the state taken to ensure the participation of children and persons with disabilities and disabled people’s organisations in the formulation of laws, policies, programs and guidelines that affect the rights of the child?
- What steps has the State taken to promote in-country adoption of children with disabilities

The Extreme Vulnerability of Children with Disabilities in Areas Affected By Armed Conflict (Articles 2, 3, 23, 24, 32, 26, 36, 37)

In India’s Report to the Optional Protocol to the Convention on the Rights of the Child on the Involvement of Children in Armed Conflict, the government stated, “**India does not face either international or non-international armed conflict situations**⁸⁶.” In other places of the same document, it was stated that India does not have any areas of armed conflict. In reality, these statements are not true. Out of the total 640 districts of India, 197 are affected by armed conflict, both internal and external. This include the state of Jammu and Kashmir, Left-Wing Extremism areas of Central and Eastern India and India’s North-east⁸⁷.

Conflict situations in India have left many children vulnerable to extreme forms of violence, break-down of protection systems, loss or separation from their families and grievous injuries leading to disabilities and long-term psychosocial effects.⁸⁸ Reports cite large numbers of “school dropouts, children entering the labour force at a premature age, exploitation, high levels of

⁸⁴ See Twenty years of CRC: A balance Sheet, **Volume 1**, CRC 20BS C/o HAQ: Centre for Child Rights, 2001, Link - http://www.haqcrc.org/sites/default/files/CRC20BS_Vol%201_1.pdf

⁸⁵ Section 9, Guidelines Governing the Adoption of Children, 2011, Link - http://adoptionindia.nic.in/guideline-family/Part_I.pdf

⁸⁶ See Point No. 15, Article 4, Page 7, Link - http://wcd.nic.in/crc3n4/crc3n4_2r.pdf

⁸⁷ Executive summary and recommendations , Page 1, Nobody’s children: Juveniles of Conflict Affected Districts of India, Asian Centre For Human Rights, Link- http://www.achrweb.org/reports/india/JJ-Nobodys_Children2013.pdf

⁸⁸ See Page No. 27, Mapping the Impact of Conflict on Women and Children, Challenges to Education in Jammu and Kashmir, Save the Children, 2011

malnutrition and anaemia, poor health and hygiene conditions and lack of psychological well being⁸⁹

Children Becoming Disabled - It has been observed that many children have expired or have become disabled due to exposure to explosive devices like landmines⁹¹ in the course of their natural activities like playing. In most cases, the support extended in the name of rehabilitation is none other than the negligible amount of the disability pension which again is available to very few children.⁹²

The evidence of children facing traumatic experiences, leading to increased anxiety and depression is overwhelming. It has also been reported by many organizations that children in areas affected by conflict have often developed mental health issues including disorders⁹³. Not only victims of violence are exposed to mental health issues but also perpetrators⁹⁴ – children who get involved with armed groups in direct hostilities as soldiers, porters, cooks etc. are directly exposed to mental health issues due to the range of hardships and traumatic experiences they face.

Barriers For Children With Disabilities Getting Multiplied – Children with disabilities face various challenges either in movement or speech or vision or communication and comprehension and such barriers gets multiplied in areas affected by conflict. Their movement gets further restricted. Situations of conflict in states like Jammu and Kashmir, Chhattisgarh, Jharkhand, Odisha, Andhra Pradesh, Assam, Manipur, Nagaland and other North-Eastern states have also led to children missing out on their classes and other activities in school as parents remain concerned about their child's safety outside home.

Of the 60 million children out of school in conflict-affected countries, 19 million are in India⁹⁵. Reports from Jammu and Kashmir show that children with disabilities are amongst the largest groups of out of school children in the state.⁹⁶ Concerns have been expressed in reports about sluggish progress regarding out of school children, children with special needs, gender disparities as well as data discrepancies. With respect to out of school children, the Sarva Shiksha Abhiyan (SSA) reports that the “State does not have any mechanism to identify out of school children.”⁹⁷

In Jammu and Kashmir, all laws specifically meant for children and persons with disabilities have not been enacted. “Although Jammu and Kashmir has passed J & K persons with

⁸⁹ Page 7 & 10, Pilot Programme for Protection of Child Rights (PPPCR) in Jammu And Kashmir Annual Report, Rights, National Commission for Protection of Child, Link - http://www.ncpcr.gov.in/annualreports/Annual%20Report_PPPCR_April_%20Final.pdf

⁹⁰ Recently an assessment of children with disabilities was conducted by SSA with the help of ALIMCO Kanpur expert team. At an average 400 children were identified in every zone of district Anantnag. 4800 hundred children in one district mean JK has about 60000 children with disabilities in the age group Of 6 – 16, all unattended, uncared – Javed Ahmad Tak by Email

⁹¹ See Page 5, United Nations Children's Fund, with inputs from other UN agencies, 'Landmines & Explosive Remnants of War: Machel review thematic paper', UNICEF, New York, 14 June, 2007, as mentioned in Point No. 143, Page 205, Link - http://www.unicef.org/publications/files/Machel_Study_10_Year_Strategic_Review_EN_030909.pdf

⁹² Page 10, Pilot Programme for Protection of Child Rights (PPPCR) in Jammu And Kashmir Annual Report, Rights, National Commission for Protection of Child, Link - http://www.ncpcr.gov.in/annualreports/Annual%20Report_PPPCR_April_%20Final.pdf & Case of Shabir Ahmad and his three friends from the Kashmiri village of Soothipora Gund, Javed Ahmad Tak by Email

⁹³ Pilot Programme for Protection of Child Rights (PPPCR) in Jammu And Kashmir Annual Report, Rights, National Commission for Protection of Child, Link - http://www.ncpcr.gov.in/annualreports/Annual%20Report_PPPCR_April_%20Final.pdf

⁹⁴ Reports say use of child soldiers are prevalent in India, See - http://articles.timesofindia.indiatimes.com/2013-05-10/india/39168410_1_child-soldiers-achr-director-suhas-chakma-recruitment; <http://www.humanrights.asia/news/alrc-news/human-rights-council/hrc6/AL-024-2007>; <http://world.time.com/2013/05/15/86532/>; <http://www.achrweb.org/reports/india/JJ-IndiasChildSoldiers2013.pdf>

⁹⁵ See Point No. 86, Page 203, Endnotes, The Machel Study 10-Year Strategic Review – Children and Conflict in a Changing World, http://www.unicef.org/publications/files/Machel_Study_10_Year_Strategic_Review_EN_030909.pdf

⁹⁶ See Page No. 9, Pilot Programme for Protection of Child Rights (PPPCR) in Jammu And Kashmir Annual Report, Rights, National Commission for Protection of Child, Link - http://www.ncpcr.gov.in/annualreports/Annual%20Report_PPPCR_April_%20Final.pdf

⁹⁷ See Page No. 7, Literature Review, Challenges to Education in Jammu and Kashmir, Save the Children, 2011, & Jammu and Kashmir Appraisal Report, Sarva Shiksha Abhiyan (SSA), 2010

disabilities Act 1998⁹⁸, its implementation is not proper. The National Trust Act for the Welfare of persons With Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities has not been enacted in the State. Important laws for the protection of children such as the **The Jammu And Kashmir Juvenile Justice Act, 1997**⁹⁹ applicable for the state of Jammu and Kashmir and **The Juvenile Justice (Care and Protection of Children) Amendment Act, 2006**¹⁰⁰ applicable to the rest of the country have not been implemented in letter and Spirit. Children, irrespective of their age, in the 197 districts which are officially notified as affected by internal armed conflicts including the 71 districts¹⁰¹ notified as “disturbed” under the Armed Forces Special Powers Act (AFSPA) are treated as adult. They are routinely subjected to gross human rights violations including arbitrary arrest and detention, torture, extrajudicial executions and sexual assaults as part of the counterinsurgency operations, which, at times also result to disability or death of children. Juveniles in these districts are denied access to juvenile justice unlike their counterparts in rest of the country. Children with disabilities are deprived of a protective framework in situations where they need it most.¹⁰²

Areas of armed conflicts are also usually characterized by lack of law and order. Draconian Laws like **The Armed Forces (Special Powers) Act, 1958**, which has even been criticized by the **UN Commissioner for Human Rights** as “dated and colonial-era law that breach contemporary international human rights”¹⁰³, gives the security forces special powers that they have been, at many times, seen misusing by unethically indulging with civilians, at many times, children. Children with disabilities, being more vulnerable than other children in regard to movement and communication, often become easy targets of exploitations. At many times minor girls with disabilities were molested, and raped in the areas affected by conflict¹⁰⁴. Asian centre for Human Rights **comments that the children in areas affected by armed conflict can be termed as – “Nobody’s Children” as they belong to the 197 conflict affected districts where in practicality the Juvenile Justice Act or its associated schemes do not work.**

- Are there any statistics available as to how armed conflict has affected children including children with disabilities in India? What measures has the government taken to eliminate abuse and violation and ensure care and protection of all children including children with disabilities living in the areas affected by armed conflict?
- What efforts are being made to provide a legal and protective framework for development, education and protection of children with disabilities in Jammu and Kashmir?

Appendix

Some Details on Reach of rehabilitation Schemes - Many major schemes were seen underperforming. The **Deendayal Disabled Rehabilitation Scheme (DDRS)** targeted to achieve only slightly over 2 lakh beneficiaries. The number of beneficiaries of the DDRS annually is only about 2.30 Lakhs (See MSJE Annual Report 2010-11 Page No. 138). The **District Disability Rehabilitation Centers (DDRCs)** that aims at providing rehabilitation services to persons with

⁹⁸ See News report Link - <http://www.greaterkashmir.com/news/2011/dec/2/-implement-jk-persons-with-disabilities-act-1998-in-letter-and-spirit-47.asp>

⁹⁹ See Act in Link - <http://eforms.gov.in/jammukashmir/sites/default/files/3180.pdf>

¹⁰⁰ See Act on Link - <http://wcd.nic.in/childprot/jactamedment.pdf>

¹⁰¹ 71 districts notified as “disturbed” under the Armed Forces Special Powers Act (AFSPA) include districts in the states of Assam, Arunachal Pradesh, Manipur, Meghalaya, Nagaland and Tripura in the north east India and 20 out of 22 districts in Jammu and Kashmir; and 106 districts declared as Left Wing Extremism (LWE) affected in nine states of Andhra Pradesh, Bihar, Chhattisgarh, Jharkhand, Madhya Pradesh, Maharashtra, Orissa, Uttar Pradesh and West Bengal, Page 1, Link- http://www.achrweb.org/reports/india/JJ-Nobodys_Children2013.pdf

¹⁰² Executive summary and recommendations , Page 1, Nobody’s children: Juveniles of Conflict Affected Districts of India, Asian Centre For Human Rights, Link- http://www.achrweb.org/reports/india/JJ-Nobodys_Children2013.pdf

¹⁰³ See Link - [http://en.wikipedia.org/wiki/Armed_Forces_\(Special_Powers\)_Act,_1958](http://en.wikipedia.org/wiki/Armed_Forces_(Special_Powers)_Act,_1958)

¹⁰⁴ See Sexual Violence section, Case 2, Page No. 7, Nobody’s Children: Juveniles of Conflict Affected Districts of India, Asian centre for Human Rights, Link- http://www.achrweb.org/reports/india/JJ-Nobodys_Children2013.pdf

disabilities by in un-reached and un-served districts of the country through providing services for prevention and early detection, referral for medical intervention and surgical correction, fitment of artificial aids and appliances, therapeutical services etc. There are 181 functional DDRCs. The number of people that the scheme have reached out to is not clear from the reports of the Ministry. Though the **Assistance to Disabled Persons for Purchase / Fitting of Aids and Appliances (ADIP)** reaches out to only around 2.5 lakhs people annually, its convergence with **Sarva Shiksha Abhiyan (SSA)** seems to have reached out to many more children than it has through its own distribution centres. According to the 2009 Annual Report of MSJE, 12.7 lakhs (1.27 million) children with disabilities have received aids and appliances under the specific plan for convergence between MSJE and MHRD. The schemes run by **the National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities** have a lot of potential but are run on such a small scale basis that their programs do not make effect on the larger population of children with disabilities. The rehabilitation services provided by the **National Institutes of Disability** through their various centres and outreach programmes reaches out to only about 4-5 lakh people annually (See Annual Report, 2010-2011, Ministry of Social Justice and Empowerment).

Appendix 2

This report is submitted to the CRC committee by National Disability Network of India. Disabled peoples organisations and leaders of the disability movement from all parts of the country are members of this network. The network has been meeting regularly over the past years to monitor the implementation of the rights of children and persons with disabilities. For the present report AARTH-ASTHA an organisation working for children with disabilities served as the secretariat for information gathering and collating this report. Members of the network who actively supported the drafting of this report with information and suggestion are as follows –

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