# Project Title

**Strengthening Community based Early Childhood care and Development (ECCD)[[1]](#footnote-2) for 25 Children with Disabilities**

# 25 years of ASTHA

ASTHA is one of the few cross-disability organizations working actively with children and persons with disabilities in urban slums and resettlement colonies in Delhi, India.

Twenty-five years ago, ASTHA started working *against* a thinking that children and persons with disabilities would remain at the peripheries of institutions and society and that they did not merit any rights but that their lives were to be managed by others. It was also believed that children and persons with severe and multiple disabilities were to remain hidden in the confines of the family. In 1993 ASTHA started with a very clear understanding that the most severely disabled person and child was going to be our first person and child and be at the centre of our work.

With a focus on building the abilities of the child, ASTHA works at the crucial job of providing the family and the major caregivers of the child with all the tools to enable the development of the child and to build their own resilience. It then widens its focus to gather all the resources in the community that can be used to support the child and focuses on the inclusion of this child and family in official institutions of society. Understanding contexts of urban slums, building rapport in the community, identification of children with disabilities are the initial steps followed. This is followed by establishing trust with the family, detailed understanding of needs and abilities of the child and subsequently training and capacity building of parents for home based and community based rehabilitation of the child. Following a multi dimensional approach the child is at the epicentre of ASTHA’s work, followed by intensive work with family, community, support systems and finally linking grassroots evidence to policy level platforms.

# Introduction

Article 45[[2]](#footnote-3) of the India constitution mandates the state to “provide early childhood care and education for all children until they complete the age of six years”. It is these early years (before the age of 5), when 90 percent[[3]](#footnote-4) of brain growth takes place. Nutrition, early education, stimulation, socialisation and protection are key pillars of holistic ECCD services for growth and stimulation of a child.The belief that all vulnerable groups of children, including children with disabilities have the right to access holistic early childhood care forms the core of this project.

This project is being run at a time when there is a global movement to ensure ECCD as a right for every child. There is a push for ECCD through international frameworks like Sustainable Development Goals and national policies like Rights of Persons with Disabilities Act (2016), National Child Policy (2013), National ECCE Policy (2013) and the *Rashtriya Bal Swasthya Kryakram* (2015) in India. As India is a signatory of the United Nations Conventions on Rights of Persons with Disabilities (UNCRPD), it should be our mandate to “take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children” (Article 7, UNCRPD[[4]](#footnote-5)).

# Rationale for the project

The human brain develops fastest in the first six years of life. Throughout our lives, our capacities keep evolving. However, the foundation is laid in the early years. The brain grows organically and more connections and synapses develop if there is good nurture, nourishment and stimulation in the early years. This is true for all, which includes children with disabilities. Holistic ECCD services should include nutrition, early education, stimulation, socialisation and protection, among other important domains.

It is imperative to comprehend the importance of inclusion of children with disabilities in mainstream settings which provide such services. Interventions in early years of a child with disability are important as these formative years influence various outcomes in the adult life. While nurture and nourishment are widely recognised as needs for child development, a stimulating environment is not always understood as an essential need for all children to flourish. Research has shown that stimulating early intervention mechanism lay the foundation for holistic development of a child in various domains. It is often seen that a child with disability is often left out of such services.

ASTHA, as an organisation has witnessed that child with disability, in a vulnerable socio-economic setting, is much more susceptible to development risks. Often, children with disabilities are most in need of early childhood care and they are the ones left out of mainstream services. There are high chances that the disability could become more severe or complex in absence of mechanisms of early identification. **ASTHA’s experience of implementing a community based Early Intervention programme in the urban slums has shown that training of families of children with disabilities is one of the most effective strategies for rehabilitation process of the child.**

# About the geographical area

Noor nagar and Shaheen bagh are parts of sprawling Muslim ghettos in district South Delhi. According to the census 2011, there are more than 16,000 households in the ward 206, which constitutes Noor nagar and Shaheen bagh as well. Both of them combined have nearly 2500-300 slums/households, with majority being belonging to Muslim communities. Situated on the right-bank of the Yamuna, Noor Nagar and Shaheen bagh are surrounded by Jamia Nagar and are a part of the densely populated Okhla neighbourhood in Delhi. The settlement itself remains one of ten-odd ghettoes that make Jamia Nagar, itself a striking imagery of radical disparities and inequities.

The geographical area and communities living are marred by several inequities and vulnerabilities. Various research studies and reports[[5]](#footnote-6),[[6]](#footnote-7),[[7]](#footnote-8),[[8]](#footnote-9) including the Sachar committee report documents that the community lag behind in a range of indicators including economic status, higher education enrollment, work participation rate etc. Across India, half of Muslim children who complete middle school dropout during secondary school, according to the Sachar Committee[[9]](#footnote-10). According to a study[[10]](#footnote-11) based on National Family Health Survey, the dropout rate among Muslims is 17.6%, higher than the all-India average of 13.2%. It has now been documented that religious, caste and various other communities need consistent affirmative action and support from various quarters. Living in such difficult situations, children with disabilities remain bereft various services which are not only beneficial for them, but also a right in their own realms.

**Both of these geographical areas are an extension of ASTHA’s current ECCD project. A wide coverage and reach out to more young children with disabilities will give a greater impetus and lead to evidence backed policy considerations for children with disabilities.**

# Our experience – taking learnings from the grassroots to the policy

Over the past two years, ASTHA has initiated intensive community based ECCD interventions. There have been a range of strategies that the organization has followed at various levels. The work starts at the community level to understand the contexts, strategizing to acknowledge and deal with myriad contexts. We find the major contexts like migration, life in urban slums and lack of extended structures.

We started to identify young children with disabilities, building trust and understanding the abilities and needs of the child through detailed discussion with family members. A major thrust area is partnership and linking of families with each other through camps, with groups of mothers and other parents coming together.

While working with over 50 young children with disabilities, it has been witnessed how the training of parents can have a huge impact in a child’s life. It was witnessed that parents do keep trying in spite of lack of information for their child. With a focus on building the abilities of the child, ASTHA then takes up the crucial job of providing the family and the major caregivers of the child with all the tools to enable the development of the child and to build their own resilience. It then widens its focus to gather all the resources in the community that can be used to support the child and focuses on the inclusion of this child and family in official institutions of society. The multi level work enabled inclusion of 25 children in the anganwadis, more than 15 children got admission in mainstream public schools and the parents developed belief in their child.

Being part of the Neenv forces alliance and Alliance for Right to ECCD enabled the organisation to push these grassroots learnings to policy deliberations. Along with this, ASTHA realized that there is an unmet need of resource material and knowledge mediums in the context of early intervention with a child with disability. The organisation envisages an information awareness training pack, which can reach out to thousands of children and their families. On these lines initial 3 videos of the series ‘Mutthi Bhar Armaan’ has been created.

1. *Mutthi bhar armaan:* A video on acceptance of children with disabilities in families

<https://www.youtube.com/watch?v=DylQ8QVEkjk&t=214s>

# *Mutthi bhar armaan:* A video on importance of play for children with disability <https://www.youtube.com/watch?v=eJ4hZTT1Tb4&t=39s>

# *Mutthi bhar armaan:* A video on importance of nutrition for children with disabilities

# <https://www.youtube.com/watch?v=VWx5jOE2B_4&t=33s>

# Objectives of the Project

The project aims to sustain ECCD interventions for children with disabilities, which can also act as a replicable model.

**Objective 1**: Facilitating intensive home based and community based ECCD services and Early Intervention mechanisms for children with disabilities

**Activities**

1. Understanding the abilities and needs of the child through detailed observation, discussion with family members - assessments
2. Work with children: Interventions with children will follow a twin track approach with children – at individual level and in groups.

*Home based work*: Home based work will be majorly done with very young children (0-3 years) at individual level and very small groups.

*Centre based and community based work*: These sessions will be done in small and large groups as per planning and will include children without disabilities as well. The focus of these sessions would remain with children above 3 years. These will be done at the centre as well as in the communities. These sessions will be planned in such a way that they learn in various domains (including preschool skills and school preparedness) in groups through various activities.

1. Inclusive creative art activities in group sessions
2. Linking/inclusion/enrollment of children with Anganwadis, schools etc.
3. Hospital visits

**Objective 2**: Working in partnership with families to enable development and rehabilitation of their child and create support structures for the family through ECCD interventions

**Activities**

1. Orientation meetings for parents of children with disabilities on importance of early childhood care and early intervention
2. Inclusive workshop for parents on preschool skills
3. Parents meeting (get togetherness)
4. Exposure visits

**Objective 3**: Creating a demand for ECCD services for children with disabilities by raising awareness in the community and involving anganwadis, primary health system and rehab systems – with a focus on identification of children with new disabilities mentioned in the Rights of Persons with Disabilities Act *(intellectual disabilities like learning disabilities and autism; chronic neurological conditions like multiple sclerosis and parkinson's disease; blood disorders like hemophilia, thalassaemia and sickle cell disease)*

**Activities**

1. Mapping of Mohalla clinics, Anganwadis, Primary Health Centres (PHCs) in the nearby areas
2. Camps/awareness drives for identification of children with new disabilities (intellectual disabilities like learning disabilities and autism; chronic neurological conditions like multiple sclerosis and parkinson's disease; blood disorders like hemophilia, thalassaemia and sickle cell disease)
3. Regular information sharing in the community through FGDs, sustained awareness programmes through discussions and use of short films
4. Regular orientation and awareness sessions with parents of children with disabilities
5. Sustaining dialogue, regular meetings working out specifics with nearby anganwadis to ensure inclusion of children with disabilities with all children
6. Sustaining dialogue, regular meetings working out specifics with nearby public schools to initiate school transitioning of young children with disabilities

# Expected Outcomes

1. Immediate and long term child outcomes of approx 25 children with disabilities are expected in the following domains:

 -Cognitive development (Age-appropriate learning, reasoning, etc)

 -Language development (Age-appropriate receptive and expressive language)

 -Social and emotional development (Positive relationships with peers and adults,

 age-appropriate expression of emotions, etc)

-Physical health and motor development (Regular health care practitioner, routine check-ups, immunizations, etc.)

1. Minimum 75% of the children with disabilities will be included in the Integrated Child Development Services
2. Age appropriate children will be enrolled in mainstream public schools
3. Legal documents (disability certificates, birth certificates, Aadhar card etc.) of 20 children with disabilities will be ready by the end of project
4. Enhance capacity of at least 15 parents or families of children with disabilities for their home based and community based care and rehabilitation
5. Around 2 community staff and 5-10 parents will get trained and empowered in the area of Early Childhood Care and Intervention
6. Minimum 10 Anganwadi workers, 5 ASHA worker and elected representatives will get sensitized about Early Childhood Care and Development
1. This document note uses the term Early Childhood Care and Development (ECCD), however similar terms are often used: Early Childhood Education (ECE), Early Childhood Development (ECD) and Early Childhood Care and Education (ECCE) [↑](#footnote-ref-2)
2. http://lawmin.nic.in/olwing/coi/coi-english/coi-4March2016.pdf [↑](#footnote-ref-3)
3. Giedd, Jay, N (2004), “Structural Magnetic Resource Imaging of the Adolescent Brain”, Annals of the New York Academy of Sciences, 1021 (1)77-85, doc:0:1196/Annals, 1308.009 [↑](#footnote-ref-4)
4. https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-7-children-with-disabilities.html [↑](#footnote-ref-5)
5. Muslim enrolment in higher education: <http://aishe.nic.in/aishe/viewDocument.action?documentId=199> [↑](#footnote-ref-6)
6. Work participation rate: <http://mospi.nic.in/mospi_new/upload/nss_report_552.pdf> [↑](#footnote-ref-7)
7. School dropout rates : <http://www.iosrjournals.org/iosr-jrme/papers/Vol-4%20Issue-6/Version-3/K04637583.pdf> [↑](#footnote-ref-8)
8. <http://www.educationforallinindia.com/How_inclusive_is_higher_education_in_india_Social_Change_2015-JBG_Tilak.pdf> [↑](#footnote-ref-9)
9. https://scroll.in/article/812272/muslims-have-the-lowest-rate-of-enrolment-in-higher-education-in-india [↑](#footnote-ref-10)
10. http://www.iosrjournals.org/iosr-jrme/papers/Vol-4%20Issue-6/Version-3/K04637583.pdf [↑](#footnote-ref-11)