

Children with Disability

Policy Framework for Early Childhood Intervention

- **Abhishek Raj**

According to the 2011 Census, 7.8 million children suffer from disabilities, out of which 42% belong within the age bracket of 10 years. In this context, it is important to understand that if the disability is recognised at an early age then it can be resolved by giving proper aid to the child. Hence Early Intervention (EI) becomes important. During the field work done in Davanagere district of Karnataka, many instances of disregard for early childhood intervention and education was seen which makes the basis for this policy paper. The first major step in this direction is recognising the disability which is barely addressed in any policy documents. This paper looks at the problem from its initial point, which is recognition and conducts an hierarchy analysis as the problem situation is based on a causal relationship. It also looks at the framework that is needed to better address the problem along with the recommendations.

Executive Summary

Children constitute 39% of the country's population (Census 2011), and are the most vulnerable group in the social structure. This is because any policy that is directed at them to be realised needs the support of the entire system. Parents, teachers, society, and government are the four major actors who revolve around the social group of children. All of these actors need to come together for any benefit to accrue on children as their age does not allow them to legally stand on their own and claim their benefits.

Early Childhood Intervention (ECI) is necessary as a study done by United Nations International Children's Emergency Fund (UNICEF) shows that 80% of the brain development of child happens below the age of 6, and any deficiency in their mental or cognitive abilities can be recovered by giving them dedicated treatment. Under the ambit of ECI, children with varying issues are dealt with, but in the fieldwork done the cases that were studied basically involved children with developmental delay or disabilities (mental/physical). The policy paper is also specific to this domain.

Issue

There is a growing recognition that the initial years of a child's life are a predominantly sensitive period in the process of development. In spite of this understanding the number of untreated cases for children with delayed development has not reduced (The Association of People with Disability, 2017).

The issue seen on the field was that the parents of children with delayed development were unwilling to admit that their child needed assistance in learning (which they read as 'abnormal' child). Another section of parents believed that the condition of their child is a direct result of a 'God-given' curse (this is more so in the case of a girl child). Both these scenarios can be interpreted under one umbrella problem, that is, non-recognition of medical condition of the child. The issue if unsolved at a young age persists for a longer duration in their adult life and may also lead to a permanent disability. According to the National Family Health Survey – 4 (2015-16) data for 15 States, 37% of children under the age of 5 showed physical deformities that were curable if treated at an early age. This shows the importance of recognising impediments in the normal development of a child as majority of the disablements are curable.

Once the issue of recognition is dealt with, it becomes easier for benefits to be directed to them and child centric policies can be made with responsibility directed at the government rather than depending on the entire system for a benefit on the child to accrue.

Studies have shown that early childhood intervention programs have yielded in benefitting the child through academic and behavioural development; it is therefore the need of the hour to heed attention to identifying disabilities in children at an early age by bringing in a policy that specifically addresses ECI as the core policy concern.

Hierarchy Analysis

The problem discussed concerns itself with the apprehensions of recognising disabilities at a young age, the societal implications that follow, and the generalisation (presuming that social structure of every region is similar) made in previous policies. Hence hierarchy analysis is used to identify and understand the possible causes for the problem situation. The causes for the problem is categorised into three kinds.

- 1. Possible causes.** Under this category, event or an action that is remotely responsible or contributes to the occurrence of the problem is recognised. In a conservative setup like North Karnataka, where superstitions and belief in their deity is very strong, religious intervention is needed to lead them into the path of developing a scientific temper or even have an objective outlook about an issue. This was not seen in these villages. There were no God(wo)men, who advocated recognition of any sort of medical condition. They on the other hand asked the people to sit for days in temples and wait for God's permission to take them out of the village where proper treatment would be given. No

lobbying or actions were taken to address this issue and hence this becomes a possible cause for non-recognition of developmental delay in children as a medical condition.

- 2. *Plausible causes.*** These causes are stated based on direct experience of field work. Interaction with parents, teachers, ASHA workers, and NGO (Spoorthy) members has shaped these causes. Superstitious beliefs have played a major role in such non-recognition. The people living especially around the village of Devarahalli (the name literally translates to the village of God) have a strong belief that God plays a major role in their lives. Every good or bad event is directly credited to God himself. During one of the interviews conducted, the parent spoke about how they sat for hours in front of God waiting for him to pay attention to their son and granting them permission to take him to a hospital. Here permission means the falling of a flower from the right hand side of the deity. Such blind following of God makes superstitious belief a strong cause for non-recognition.

Another such cause is parents not accepting of the fact that their child needs special medical attention. As we went around villages to recognise children who need special attention, we were directed to a few houses by Anganwadi teachers and ASHA workers who were trained to recognise such children. When we approached the parents, even though the language used was very mild without giving a hint of their child's developmental delay, they were aggressive and did not mince words to send us away. After speaking to village panchayat members about the issue, we were made aware that this was a very common reaction especially in houses that held a formidable position in the village (Upper caste/class).

These two causes have a significant influence on the problem of non-recognition.

- 3. *Actionable causes.*** Within this category the factors that are subject to control by policy makers is recognised. The government has not taken enough measures to reach out to people in villages about such medical conditions. They have not sensitised them about the commonality of such occurrence. This has not helped people in developing an objective stand on the condition of their children.

Charted Path Based on Identified Causes

The problem here has been identified based on the percentage of people who have failed to recognise a medical condition that can be treated if reported at a young age. Around 50% of people interviewed believe that they have to look at the issue objectively but they did not have enough courage to go against the established practice of presenting the child to their deity and obtaining permission to get them treated. In order to help them gain courage over the matter, the third cause has to be elaborated, that is, sensitisation of such issues. Rather than a rational appeal, a more emotional appeal has to be made to address such concerns. The government has identified civil societies to conduct sensitisation programs and has helped them by

funding, but a government mandate that specifically addresses the issue is very much needed. Such sensitisation programs if conducted by village heads (those who usually win or become kingmakers) would wield significant influence on people and might have a chance to tackle this problem.

Currently the government has many schemes through which children with such a medical condition can be benefitted. These benefits are only given to children above the age of 6 years. Early Intervention ends at the age of 6. Hence the government needs to rethink its incentives and direct them to the age bracket of 3-6 years. Enough economic incentives might also help the parents from economically disadvantaged condition to come out with their children’s condition.

Policy Alternative

The current policy, National Early Childhood Care and Education (ECCE) Policy provides for ‘holistic development of all children, along the continuum, from the prenatal period to six years of age’. Though the policy lays down a comprehensive approach towards ensuring a thorough foundation for the child, it does not detail the path in which the intended objective would be achieved.

This policy does not consider the regional apprehensions that need to be addressed as parents of the concerned children have different outlook depending on the place or social construct they come from. It also does not identify non-recognition of delay in development by parents as an issue that needs to be addressed.

ECCE policy should encompass both these issues as they determine the success of the effective implementation of the policy at grassroots level. To achieve this, the policy framework should rather be child centric than enveloping the actors around children in the society through social responsibilities. The other component is inclusion of regional variables.

Policy Framework	Argument
Child Centric	If the child is put at the centre of the framework, it becomes easier to direct the benefits at them. A child-centred approach recognizes that children’s rights and needs are the primary focus for development. Since numerous institutions are accountable for fulfilling the rights of children, a child-centred approach inevitably requires strengthening social systems for care and well-being of the entire society. Establishing community based basic social services systems and developing the competence to manage and sustain them should be made a priority. Such community capacity building is obviously based on developing systems of co-operation, support and management in communities to ensure child-care and development.

Regional Variables	Every region has its own social construct. Families usually bow down to the traditions that are followed by the society. So the policy framework must include regional discrepancies in its discourse as it would be able to better solve the issue at hand.
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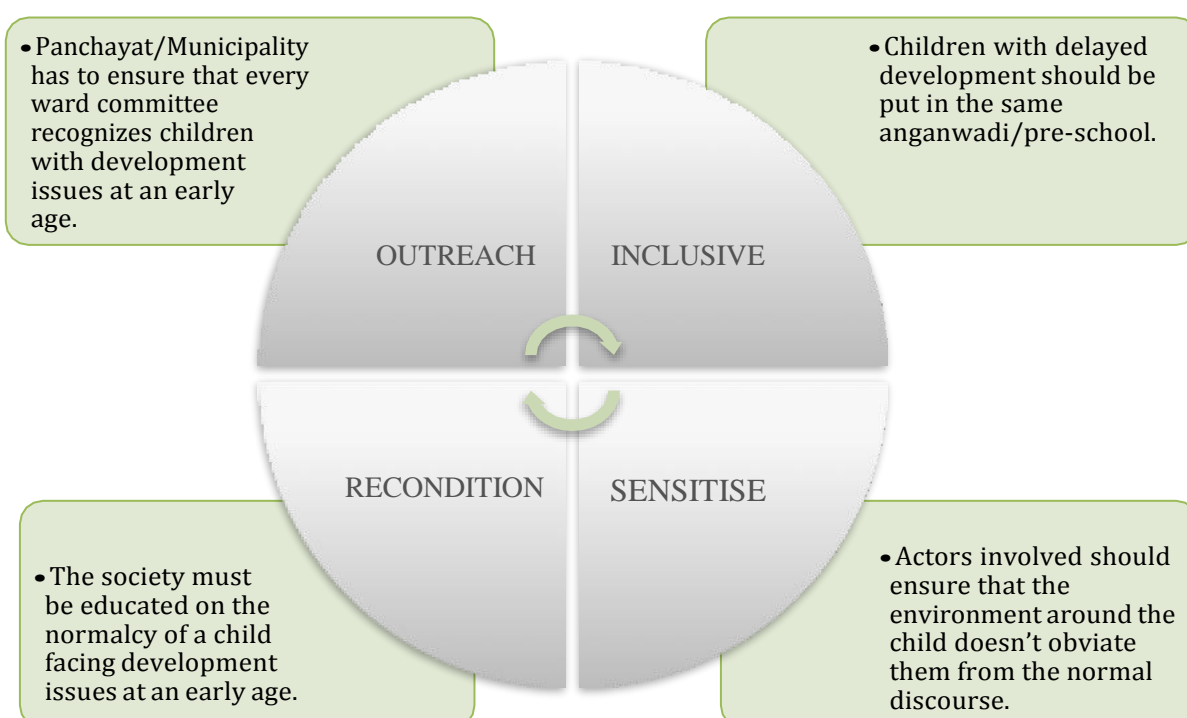
Elements of the Alternative Policy

Involvement of Anganwadi Teacher and ASHA worker. The teacher and Accredited Social Health Activist (ASHA) must be trained to identify children with delayed development and notify them to the Panchayat, who would contact the government agency that specialises in addressing the specific case. For this, both the professionals have to be trained in the basics of child developmental stages. They should be sensitised and taught to address concerned parents about the disabilities of their child with a tone of normalcy. This would encourage the parents to send their children without any apprehension of their child being treated as abnormal by the society.

Involvement of Religious representatives. In some places it is seen that a child's irregularity of growth is seen as a curse given by God. This can be solved by involving religious representatives who are sensitised to such issues. If they are lobbied to help solve the issue, they would add a social validation and hence more children would be recognised.

Regional Approach. The current policies are also drafted at a national level. The problems that are seen at grassroots level are very unique to a place. It is therefore important to evolve policies that are regional as they would better address the issues.

The O-I-S-R Framework. It is necessary that the policy must include a mechanism with which it must go about conducting a program. To address that issue, a fourfold framework can be used which lays out a road in which the problem can be dispensed.



Conclusion

The lives of children are a true indicator of the strength of a community and the country at large. If the youngest and the most vulnerable are left to find its way alone, then the country jeopardises its future. Hence it is important to ensure that children are kept out of harm's way. Around 3 million of this young population (below 10 years of age) delves in some sort of disability and the onus of treating them falls on the society as children are a vulnerable social group. In this population of disabled, it would have been interesting to see how many would finally be categorised as disabled if they had been treated at an early age. Given that the scientific community has come up with enough evidences to suggest that delayed development and disabilities of a certain kind can be rectified at an early age, the policy must be oriented towards recognising as many cases as possible. Hence a child-centred approach with focus on recognising the problem at an early age should be the core focus in a policy framework of Early Childhood Intervention (ECI).

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