

Working with Families Using a Family-Centered Approach for Improved Development Outcomes in High-Risk Children

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How to cite this article:

Aarti Nair, Ajay Sharma, Sandeep Kumar, et al. / Working with families using a family-centered approach for improved development outcomes in High-risk children. / Physiotherapy and Occupational Therapy Journal. 2021;14(1):9-17.

Abstract

Introduction: Around the world, almost half of all deaths in children under five occur in the newborn period. Ninety-nine percent of newborn deaths are in low- and middle-income countries and prematurity, intrapartum-related neonatal deaths ('birth asphyxia'), sepsis and meningitis account for 75% of these¹. Developmental disability is a diverse group of chronic conditions that are due to mental or physical impairments that arise before adulthood. Developmental disabilities cause individuals living with them many difficulties in certain areas of life, especially in "language, mobility, learning, self-help, and independent living"².

Aim of Study: To analyze the impact of family centered-approach on child's development outcomes. To quantify and validate the advantages of family-centered- approach for parents and children.

Method: A low-cost, family-centered intervention programme to promote child and family wellbeing is provided at an Early Intervention Centre in Latika Roy Foundation, Dehradun, India. It follows a family-centered approach of empowering families through respect, collaboration, information, training and support. The effectiveness of this methodology is evaluated in this study.

Discussion: This study evaluates the effectiveness of this family-centred interventions programme, provided by early intervention Centre, for improving development outcomes of high-risk infants. This study explores, for the first time in a resource limited country, the relationship between the reduction of family stress achieved through a family empowerment programme and improvement in development outcomes of high-risk children. Families of High-risk infants enrolled at the Centre during January 2015 through July 2017, who were in NICU for 5 or >5 days are partners in the study.

Conclusion: The importance of family-centred care cannot be over-emphasized. Early intervention services and support to families can significantly improve quality of life of high-risk children. Intervention studies for children with disability state that the best way of improving children's outcomes is by empowering parents through a structured learning programme. Given the scope and potential of such programs, this study quantifies and validates the advantages of the family-centred approach.

Keywords: Family-centered; High-risk infants; Development outcomes; Early intervention and Stimulation.

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Introduction

Around the world, almost half of all deaths in children under five occur in the newborn period. Ninety-nine percent of newborn deaths are in low- and middle-income countries and prematurity, intrapartum-related neonatal deaths ('birth asphyxia'), sepsis and meningitis account for 75% of these. As improved obstetric and neonatal care is scaled up in LMICs, the number of children

surviving these neonatal conditions at high risk of neurodevelopmental impairment and disability increases with an estimated risk of around 40% of at least one impairment in any developmental domain after perinatal insults. Intrapartum-related neonatal encephalopathy alone causes an estimated 42 million disability-adjusted life years.

The International Classification of Functioning, Disability and Health (ICF) provides a useful framework for understanding disability; structural and functional impairments, and resultant activity and participation limitations influenced by personal and environmental factors. The ICF framework and WHO Community-Based Rehabilitation (CBR) guidelines are valuable reference tools in the development of early childhood interventions (ECI) and their use is advocated by Yousafzai et al. in their review of interventions for children with disabilities in LMICs. Nonetheless, other approaches can and have been used to successfully develop ECI¹.

Developmental disability is a diverse group of chronic conditions that are due to mental or physical impairments that arise before adulthood. Developmental disabilities cause individuals living with them many difficulties in certain areas of life, especially in “language, mobility, learning, self-help, and independent living”. Developmental disabilities can be detected early on and persist throughout an individual’s lifespan. Developmental disability that affects all areas of a child’s development is sometimes referred to as global developmental delay.

The most common developmental disabilities are:

- Down syndrome is a condition in which people are born with an extra copy of chromosome 21. Normally, a person is born with two copies of chromosome 21. However, if they are born with Down syndrome, they have an extra copy of this chromosome. This extra copy affects the development of the body and brain, causing physical and mental challenges for the individual.
- Fragile X syndrome (FXS) is thought to cause autism and intellectual disability, usually among boys.
- Pervasive developmental disorders (PDD) are a group of developmental disabilities that can cause significant social, communication and behavioral challenges.
- Fetal alcohol spectrum disorders (FASD) are a group of conditions that can occur in a person whose mother drank alcohol during pregnancy.
- Cerebral palsy (CP) is a group of disorders that affect a person’s ability to move and maintain balance and posture. CP is the most common motor disability in childhood.
- Intellectual disability, also (sometimes proscriptively) known as mental retardation, is defined as an IQ below 70 along with limitations in adaptive functioning and onset before the age of 18 years².

Maternal and new-born health has long been a priority in India. Our country nevertheless still accounts for almost a fifth of maternal deaths globally each year. Access to services has increased in recent years but still, only less than half of all deliveries occur in institutions. A combination of legislative initiatives, family advocacy efforts, theory and research has led to wide acceptance of the assumption that early intervention exists not just to improve outcomes for children with disabilities but also to support their families, especially in rural India^{3&4}.

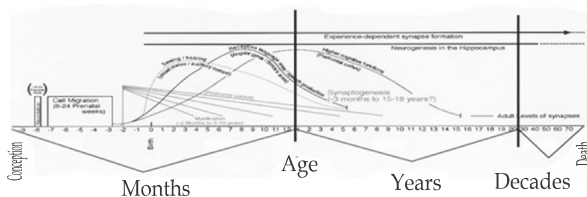
Under NRHM and RCH-II (Reproductive and Child Health Programs) India has witnessed a significant increase in the proportion of deliveries at health facilities, primarily owing to the JSY (Janani Suraksha Yojana) scheme. The health system, however, has been unable to expand the supply of services to keep up with the increased demand. In particular the high demand at secondary and tertiary care centers has resulted in massive overcrowding and an inevitable decline in the quality of care received by women and new born. This only increases the vulnerability of high-risk infants.

The most recent ASER (Annual Status of Education) study results state how cognitive levels of children are directly related to the stimulation and early intervention. Family-centred care is a service delivery model where parents serve as key informants and decision makers in the service delivery process for their children. It ensures that parents have ultimate control over decision making. It involves, treating parents respectfully, supportively and providing parents with needed information⁵.

This study involves evaluating the effectiveness of a family-centred program, for improving

outcomes of high-risk infants. A low-cost family-centred intervention programme to promote child and family wellbeing is provided at an Early Intervention Centre in Dehradun, India. A partnership with parents to support parents on how to observe and how to transfer skills at home for their children, for the best results. Intervention studies for children with disability state that the best way of improving children's outcomes is by empowering parents through a structured learning Programme. The effectiveness of this methodology is evaluated⁶.

cognitive skills and facilitates learning for all children, including the high-risk babies, who are born with multiple risk factors negatively affecting their development. The family though eager to support the child often does not know what to do, generating stress for the family and creating further negative stress for the child. Enabling families to provide the required stimulation and care is a key strategy for improving children's outcomes. Studies have proved that early identification is critical to development of brain leading to positive outcomes.



Thompson, R.A., & Nelson, C.A. (2001). Developmental science and the media: Early brain development. *American Psychologist*, 56 (1), 5-15.

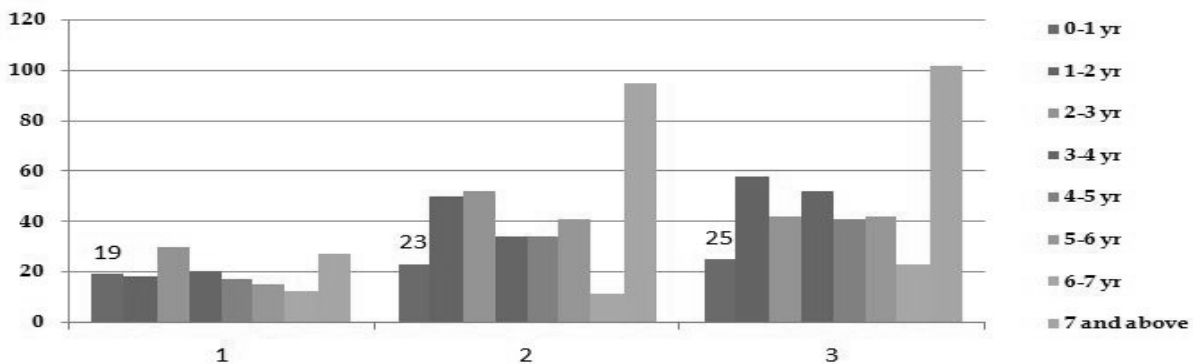
Graph 1.1: Human Brain Development.

Background

Responsive and stimulating care, early in life, fosters the development of language and

Conceiving the Idea

- a. In the early years of inception of Early Intervention Centre, it was observed that the average age of first assessment of a child with developmental delays continued to be 3-4 years. It is a well-recognized fact that the period of birth to 2 years is the critical window for promotion of good growth, health, behaviour and cognitive development and this "critical window" was missed.



Graph 1.2: Graph shows the age wise distribution of number of children assessed in the years 2011-2013.

This graph shows the age wise distribution of number of children assessed in the years 2011-2013.

(1-2011,2-2012,3-2013). at the Early Intervention Centre of LRF. Less than 70 children under the age of 1 year came for assessment in the 3 year period.

- b. A method to reach and address high-risk babies before they were 3 years of age was crucial. A cost-effective, easy to access method that had the ability to convince parents to avail the early intervention services at the centre was conceived. Amongst the first things was, setting up a kiosk within the

premises of the busiest District Govt hospital of the state. The kiosk was situated just outside the Neonatal Intensive Care Unit of the District Government Hospital in Dehradun. The kiosk outside the Neonatal Intensive Care Unit (NICU) at Hospital had 2 social workers who have done a 6 months course on GMCD. The social workers or Child Development Aids (CDA's) work was to register the names of families whose babies were admitted in the Neonatal Intensive Care Unit (NICU) using a standard protocol. The CDA's who sat at the kiosk

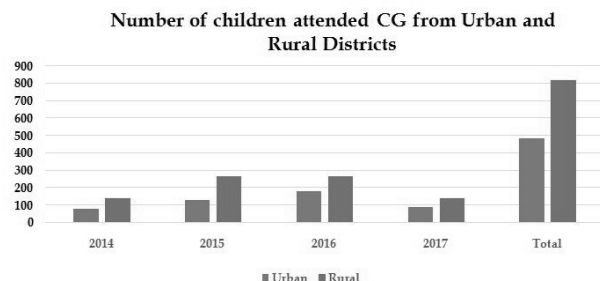
in the Women’s section of the District Hospital visited the family of each NICU baby soon after admission. The initial visit was to provide emotional support, especially to mothers, and general information. Second and third visits were scheduled as needed. The young mothers were helped in breast feeding, Kangaroo Mother Care, advise on hygiene and diet. Before discharge, families whose babies met the criteria for referral to CG were visited again and given more information about the importance of follow-up and instructions for their appointment. Prior to the appointment date, the CDA called families several times to explain the importance of regular follow-up for their child’s development and to remind them of the date and time they are expected to come to CG.



Fig. 1.1: Shows the training of parent in hospital

Description of the study

Infants meeting the established criteria were seen at CG for follow-up at 3 months, 6 months, 9 months and one year as a routine. CG follow-ups were held every Wednesday as that is the National Immunization Day. Families were seen by a multidisciplinary team including a paediatrician, two physiotherapists, a special educator and a counsellor. CDAs were available to meet them to discuss common concerns (feeding difficulties, sleep issues, etc).



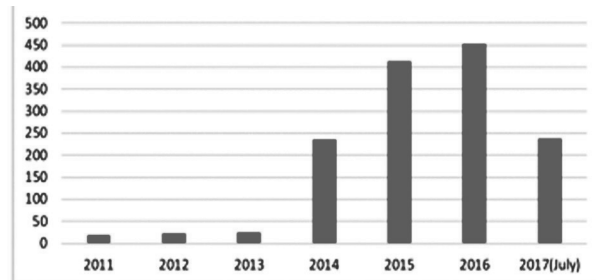
Graph 1.3: Graph shows the Number of children attended CG from Urban and Rural Districts.

Direct Support

The appointment of babies at the centre was on Wednesday as it is the National Immunisation day making it convenient for the parents to attend. When the parent attended the follow-up program they found the same familiar face of the CDA as the point person for the day and a lot of their inhibitions and worries were put to rest.

A typical Chota Gubbara session consists of a medical examination and developmental assessment conducted by a pediatrician and physiotherapist using standardized checklist, followed by a functional assessment conducted by special educator and a CDA. Parent concerns are noted and addressed, referrals are made for further investigations as required and suggestions are given in pictorial form for development ally appropriate activities parents can carry out at home keeping the family-centred approach as the focus.

Babies whose development was age-appropriate would exit the program at any subsequent visit as determined by the project head. The emphasis throughout is on parent empowerment through a family-centred, strengths-based approach.



Graph. 1.4: Shows the dramatic change in number of babies attending the EI program after CG was started in the year 2014.)

Families are convinced of the efficacy of the program and the positive developmental outcomes for their baby.

The EI services are family-centred, family choices are the centre of the mode land it is reinforced by collaborative partnership between family members, EI professionals. Parents are equally involved in the process as active participants so they recognize their role in the lives of their children. It has led to more confident parents and reluctance to exit the program even when the baby is developing well.

Indirect Support

Many children seen at CG for an initial assessment could not return for scheduled follow-ups because of distance, poverty or difficulty in traveling. For these children, a monthly follow-up program is

held in the four largest blocks of Dehradun district and in the further flung mountain districts once a year. Families are informed well in advance that a team will be present in the government Community Health Centre. The team consists of a therapist, a special educator, a child development aide and a driver. A thorough review of the plan was done, new exercises or strategies developed in partnership with the parents and practiced before the session is over. New pictorials are given for future reference.⁶

Aim of Study

1. To analyze the impact of family-centered-approach on child's development outcomes.
2. To quantify and validate the advantages of family-centered- approach for parents and children.

Need for Study: Still now there is no any study done on working with families using a family-centered approach for improved development outcomes in High-risk children so here need study is arises.

Research Hypothesis

Experimental Hypothesis: There is significant difference in working with families using a family-centered approach for improved development outcomes in High-risk children

Null Hypothesis: There is no significant difference in working with families using a family-centered approach for improved development outcomes in High-risk children.

Review of Literature

Bronfenbrenner&Ceci, S. J. (1994) stated that, in the first two to three years the growth and development of the child is at its greatest. It is during this first phase of cognitive development that intelligence and behaviour begin to evolve. Additionally, plasticity the ability of the brain to effect structural and functional changes caused by external and internal influences is at its peak in the 0-2 year. The malleability of the developing brain at this stage makes it possible to bring about many changes. If a child misses this opportunity, further learning is slow or inadequate.⁷

Rosenbaum, Mesterman (2009) et al. states that can Child Centre for Childhood Disability Research stated that, a successful EI program is one that is family-centered. A family-centered approach keeps the concerns and decisions of the family

as the priority. Parents understanding of their child's needs, capacities and potential is more than any other person's, with this philosophy in mind the family-centred approach is considered more advantageous than any other model when it comes to optimizing outcomes for the children. This approach helps in building parent understanding of their child's condition and ways of supporting his/her development. It strengthens parent-child bonding and teaches parents how to play and engage with their children in meaningful ways. Most importantly it reduces the stress in parents and thereby leads to a happy environment, improving development levels through stimulation, play and routine activities. The way is which professionals support children with disabilities and their families has the potential to enhance or impede child and family outcomes. Currently family-centered approach underpins many models of service delivery and recognized interrelatedness of family members and importance of acknowledging the needs of all family members and not just the children with disabilities.⁸

Bailey, Bruder, M. B., Hebbeler, et al. Recommended outcomes for families of young children with disabilities. To this end, dependent variables identified in selected studies include parenting stress, competence and aspects of child development and behavior. Some child and parent characteristics may however be identified as moderating variables. Children born into poverty start at a big disadvantage. To thrive they need food, shelter, and health care. But a growing body of evidence shows there are other ways to help close the vast gap in development between poor kids and their wealthier peers- singing, talking and playing with them. Dealing with stress of poverty makes it hard for many parents to establish crucial bonds with their babies- bonds that lay the foundation for learning, emotional regulation and relationship. Poor parents are focused on survival and illness, food and health care. They have no time to play with their children.⁽⁹⁾

Butler, C. (1995) stated that, infants that appear well but have any of the following features are regarded as high-risk infants and are therefore likely to develop a problem during the newborn period.

- i. Infants that are born preterm (<37 weeks) or post term.
- ii. Infants with birth weight (<2 kg).
- iii. Wasted infants.
- iv. Infants who have low (1 min Apgar score).

- v. Infants who have a complicated delivery.
- vi. Infants who have had one or more clinical problem since birth.
- vii. Infants who are sick but have recovered.

Sick infants are those who have had infection, hypoxia, hyperglycaemia (High blood sugar) jaundice, trauma, hypothermia, acute blood loss, anemia or hemorrhage. High-risk infants are kept in neonatal intensive care units (NICU) for a certain length of time. At the NICU infants are treated and supported according to their medical needs. They are kept in incubators to maintain body temperature, most are fed nutrients through a drip until they are ready to digest and absorb milk. Only when they breathe, retain their feed and are capable of maintaining their body temperature are they discharged. Given their initial medical problems babies at risk may face development delays in childhood.¹⁰

Methodology

Sample

81 families recruited for this study (Recruitment Criteria: families of Infants who were at high-risk at birth. A low-cost, family-centered intervention programme to promote child and family wellbeing is provided at an Early Intervention Centre in Latika Roy Foundation, Dehradun, India. It follows a family-centered approach of empowering families through respect, collaboration, information, training and support. The effectiveness of this methodology is evaluated in this study. Inclusion Criteria-The inclusion criteria for the study was high-risk infants, below the age of 1 year at the time of registration and enrolling at the Centre during January 2015 through July 2017, who were in NICU for 5 or >5 days. Exclusion Criteria-High-risk infants, below the age of 1 year at the time of registration and enrolling at the Center during January 2015 through July 2017, who were in NICU for less than 5 days.

Procedure

The families served through this centre are the cohort for this study. The research design is Cross-sectional. A Mixed Method (combined quantitative and qualitative) is used. 81 families were recruited for this study (Recruitment Criteria: families of Infants who were at high-risk at birth, born in the Government Doon Hospital, Dehradun and admitted in NICU due to complications during

birth.. Primary data was captured through interview and questionnaires administered to respondents living in Dehradun whose infants were at high-risk at birth.

The following tools were used to gather data as the primary source

The GMCD, The international Guide for Monitoring Child Development (GMCD encompasses bio ecological theory and family-centred care (6) theories and monitors development across different developmental domains. The GMCD embraces the idea that child development is a spectrum, ranging from optimal development to severe developmental difficulty. It seeks to avoid labelling children, instead acknowledging our current understanding of multiple strengths and vulnerabilities in the child, the care giving environment and the community that contribute to child development.¹¹

The Quality of Life of children- Quality of Life (QoL) tool was used to ascertain whether we are making the desired difference in the life of the child. We have designed a developmentally and culturally appropriate tool for measuring the QOL, in collaboration with parents of children with disability, for pre-school children in India¹²

Data Analysis

Qualitative and quantitative analysis was done to explore any relationship between the perception of care provided with family stress, QOL and developmental outcomes.

Primary Data that is collected was after taking consent from families who are part of the research study. The consent form is based on WHO norms.

For analysis of data was done in SPSS software

Result

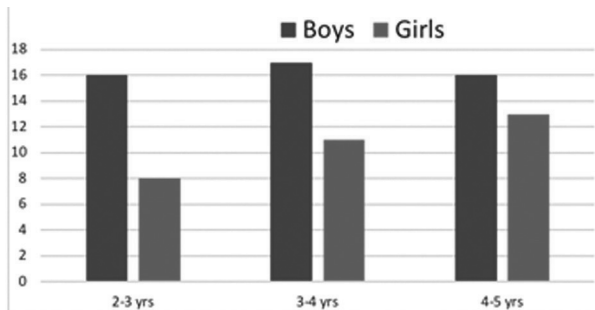
Description of Families

Most respondents (87%) were from 2 parent families, considered Hindi to be their first language (97%) and lived in urban settings (80%). The majority (64%) had a family income between Rs10,000-30,000 and mothers (63%) had education up to high school, and fathers (76%) had education up to high school. Their children with disabilities ranged between 2-5 years and their primary problem was delayed Speech and Language (63%).



Process of Study

The evaluation study of CG started in the month of Jan 2019 by collection of data and documenting the data into groups. Group A consisted of families who were registered in CG and availed the Family Centred Care(FCC), Group B consisted of families who were registered and did not attend the CG and have not received intervention in the family centred approach(Non FCC). A list of 2500 families were registered during 2014-2017 and they were called individually and informed about the study and the reason for calling.

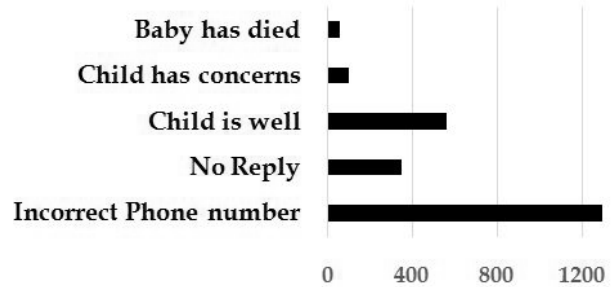


Graph 5.1: Shows Gender Ratio of boys and girls

67 families were part of the study according to the inclusion criteria, 30-37 families in each of the 2 groups i.e., 37 Children who attended the family centered care program (FCC) at the CG, and 30 families whose children were admitted in NICU but did not attend any family centred intervention program (Non FCC).

Family-Centered Care

From the study it is apparent that children who availed the EI services had improved outcomes. More than 500 children screened and monitored have age appropriate development. In the group of children attending school and the level of play is interactive (94%). Children in the age group of 2-3 years are speaking in short sentences, and are independent in activities of daily living (eating and toileting). 3-4-yearold's have greater language and cognitive development and are physically active. The 4-5-year old's prefer to do all their activities independently, are able to tell stories in sequence and sing poems.

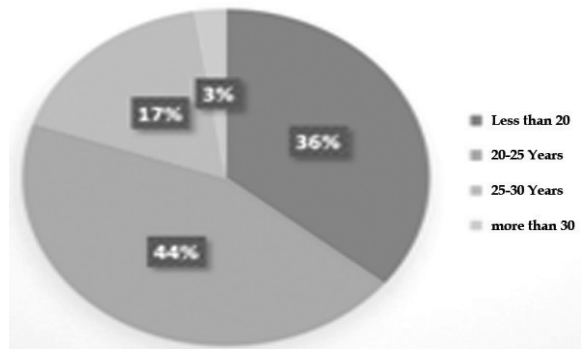


Graph 5.2: Shows of data of death and well child

Children who have concerns continue to attend the programs. From the parent interviews that were conducted it is apparent that they feel supported by the care and services provided at the EI centre even when the progress of the child is slow. They are aware of the prognosis and mindful of their child's condition and are motivated to continue regular therapy in the centers. Family-centered care leading to higher satisfaction and better emotional well-being of the families.

Non-Family Centered Care

A number of home visits were done where families could not be reached telephonically. Children born in Doon Hospital and admitted in NICU were followed up during the home visits.



Graph 5.3: Shows Chart title

Children with seemingly mild delays were not speaking in sentences and cognitive levels were not age appropriate. The receptive language was delayed and levels of play was non-interactive play. Mothers were unable to spend time as they were all daily wagers, some children would attend the Anganwadi for 2-3 hours when the Anganwadi staff would go and pick them up and bring them. The quality of life is poor and the development is delayed. Some elder siblings take care of the younger siblings (38.3%). A few grand-mothers were involved with their grand children and the children were cared for (12.7%).

Child's functional dependence and severity of

disability is related to psychosocial life stressors. The stress levels in the young mothers were high and a sense of helplessness at the condition of their children and no hope of much improvement was apparent. On being told that therapy would help they said it would not be possible to attend the program as they were daily wage earners. A large number of very young mothers are unable to deal with child rearing, contributing to the fact that children do not flourish either through neglect or abuse or both.

Wide disparities exist between different sections of population in terms of them getting quality of service leading to better outcomes for their babies. A mother living in urban area is twice as likely to get skilled delivery care as compared to a mother living in rural area. Similarly, a mother from a poor household is four times less likely to get skilled care as compared to a mother from a rich household.

Discussion

Infants who receive early developmental care demonstrate improved neuro developmental outcomes. Therapists trained in Early Intervention practices have contributed in developing parents' skills to improve outcomes in their children. CDAs are a low-cost investment making a major improvement in engaging the hard-to-reach high-risk infants by building a relationship. This study has contributed to further championing the role of family in child development, understanding what causes them stress and analysing what best supports their child's progress

The Report acknowledges that family-centred, early intervention programs are complex to implement and requires a fine understanding of diverse needs of children and their families across different contexts. India has made considerable progress in terms of putting in place a robust legal framework and a range of programs and schemes that have improved enrolment rates of children with disabilities and maternal schemes for providing medical facilities in remote areas. Implementation can be improved through better provider training, parent feedback and monitoring mechanisms. Moreover, unless persisting structural challenges are addressed implementation of family-centered care in facilities will not be effective. Capacity building in parents is the only way to achieve lasting progress for our kids. When parents learn in an easy, creative manner to make exercise fun and part of daily activities, kids will want to cooperate and development outcomes will be.

Future Goals

Creating a family-centred module for early detection and monitoring of child development for Primary Health Centres in rural areas with trained therapists to monitor and provide early intervention services. In a developing country like India where efforts are being made to address malnourishment in children and improving tertiary care services for mother and child in the first 1000 days, there is considerable lag in meeting goals. Module of early identification and intervention will be one of the strategies for covering the gap. When an infant is at risk of development delay certain standard procedures and practices should be made mandatory so that there is no delay in receiving information.

To provide a model for an effective parent-mediated, low-cost service, for Government Health Centre's to improve developmental outcomes and reduce stress in families. Time has come to employ practical, cost-effective techniques that can be implemented across the states. For a child to lead an active life and grow up to be a healthy individual it is important to provide quality care in the initial years. There is increasing awareness among Governments and corporates to focus on this crucial aspect. Existing services can be strengthened and regular monitoring programs can be implemented without delay.

Limitations

The study acknowledges that family-centred, early intervention programs are complex to implement and requires a fine understanding of diverse needs of children and their families across different contexts.

This study was conducted in the Hill state of Uttarakhand in Northern India the percentage of high-risk children is 30% as per a Unicef India Report whereas the states in South India the percentage of high-risk children is less than 12%. There is huge disparity among various states in a developing country like India. Uttarakhand being a hill state, accessibility to health services is limited due to limited infrastructure and limited public transport facilities. One of the biggest limitations to the study was inadequate tertiary care facilities and lack of awareness about developmental delays and high-risk factors. Families have little access to accurate and comprehensive information about health material, neonatal and child health practices, social services and Government Entitlements and how to use them. The State Government is working

towards providing tertiary health care services through projects like NRHM but the magnitude of problems is huge. Besides the logistical problems there are limitations to the study. The awareness for effectiveness of early intervention services is low. The process of reporting by the parents to health care providers is not consistent. There is huge stigma to any delay in child development so honest reporting of child's development is questionable.

Groups such as rural communities and minorities have a higher infant mortality rate. Social norms and cultural factors often affect the acceptability to scientific health care and nutrition as well as water and sanitation services and other basic facilities in many regions of Uttarakhand. Early development assessments are considered secondary to the primary issue that is of survival. Adequate skills for convincing parents is another limitation. Staff with professional knowledge and skill are limited in number and have to depend on reports provided by CDA's.

Conclusion

Infants who receive early developmental care demonstrate improved neuro-developmental outcomes. Therapists trained in Early Intervention practices have contributed in developing parents' skills to improve outcomes in their children. CDAs are a low-cost investment making a major improvement in engaging the hard-to-reach high-risk infants by building a relationship. This study has contributed to further championing the role of family in child development, understanding what causes them stress and analysing what best supports their child's progress. The report acknowledges that family-centred, early intervention programs are complex to implement and requires a fine understanding of diverse needs of children and their families across different contexts.

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