# Inclusive Early Childhood Development – an Underestimated Component within Poverty Reduction

Disability and Development Cooperation
(Behinderung und Entwicklungszusammenarbeit)
Caritas international/Germany
Kindermissionswerk „Die Sternsinger“
Kindernothilfe (eds.)

This publication contains the lectures and results of the international conference: Inclusive Early Childhood Development – an Underestimated Component within Poverty Reduction, which took place in Bonn, Germany from 3-4 February 2011.

The conference was organised by:
Disability and Development Cooperation
(Behinderung und Entwicklungszusammenarbeit - bezev)
Caritas international/Germany
Kindermissionswerk „Die Sternsinger“
Kindernothilfe

Additional sponsorship for the conference and publication from:
Church Development Service
(Evangelischer Entwicklungsdienst - EED)
Gesellschaft für Internationale Zusammenarbeit (GIZ)
Misereor
Stiftung Umwelt und Entwicklung Nordrhein-Westfalen

Editor: Gabriele Weigt
Translator: Brian Strevens

Essen 2011

Layout: Amund Schmidt
Cover layout: Christian Bauer, studiofuergestaltung.net
Photo: Kindernothilfe
Printers: Druckerei Nolte, Iserlohn, Germany

Institute for Inclusive Development:
ISBN: 978-3-00-036404-4

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# Introduction

The present documentation covers the lectures and results of the international conference of the same name, which took place in Bonn, Germany, from 3-4 February 2011. The conference consisted of a two-day programme which aimed not just to demonstrate the significance of inclusive early childhood development, but at the same time to present concrete solutions and possibilities of how an inclusive early childhood programme could look like. The express focus was not just on strengthening early childhood development but rather on inclusive early childhood development. This means all children, children with disabilities and other marginalised groups as well.

Human early childhood development has played a very subordinate role in the development policy discussion up until now. According to UNICEF, the first years of life receive the least attention and investment from governments. From the approximately 132 million children born worldwide every year, many do not receive the necessary attention, nutrition, health care, nurture and protection they need for a healthy development. This may be surprising due to the major intrinsic significance of this first phase of life for the developmental potential of individuals and society. According to expert opinion, the sectors of health and demography, especially measures in the areas of child health and reproductive health, were 35 per cent responsible for the economic upturn in Asia from 1965 to 1990.

The rights of children are embodied in various human rights documents. But their human rights are still disregarded millions of times over. Every year, 9.2 million children (2009) still die before reaching the age of five (or one child every three seconds), mainly due to avoidable factors such as malnutrition, lack of obstetric help, pneumonia, diarrhoea, tuberculosis, measles or AIDS.

But even if the children survive, all too often they cannot thrive, having acquired poverty-related forms of physical and/or intellectual impairment or developmental delay. According to UNICEF, these are at least 10% of all children, in other words more than 200 million. An even larger number suffer from limited learning skills and other disabilities preventing them from being able to develop to their full potential. These are the forgotten victims of poverty. It is a quiet tragedy, taking place every day and all too little perceived by the world

community. Appearing in the headlines and the majority of statistics are the children dying because of poverty. However, the children who survive this situation, but whose lives will be affected for a long time, lead a shadow existence.

Early childhood development is an important factor towards achieving the Millennium Development Goals. Seven of the eight goals directly concern the survival and development of children, meaning all children. It is therefore of great importance to significantly increase the commitment in this area so that the development goals can be attained.

The first part of the documentation therefore focuses on the question of how early childhood development can be strengthened. The contributions demonstrate what consequences poverty has on human development and how negative consequences can be avoided. In the second part, the specific focus is on the inclusion of children with disabilities in early development programmes or rather on the design of inclusive early childhood programmes. While the majority of the contributions deal with the situation in the so-called developing countries, two contributions shed a self-critical light on the situation in Germany, where there are also children living in poverty and where inclusive early childhood programmes are thin on the ground.

# Part I: Early Childhood Development and Poverty

# The Risks of Poverty to Child Development. Inclusive Early Childhood Development – an Underestimated Component within Poverty Reduction

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Early Childhood Development (ECD) as one of the main UNICEF's priorities has remained high on the organizational agenda over the past decade. Both the previous and the current Global Mid Term Strategic Priorities (MTSPs) include ECD, or more specifically two out of five global MTSPs are related to ECD: MTSP 1 on the Young Child Survival and Development includes support to very young children (0-3 years old) and their mothers and is related to essential health, nutrition, water and sanitation services and programs, as well as support for young child and maternal care at the family, community, service-provider and policy levels; and MTSP 2 related to Basic Education and Gender Equality focuses on developmental and school readiness and transition to formal schooling and is related to children 3-6 years of age.

UNICEF programming and work in ECD is grounded on the strong and clearly established evidence about the importance of investing in ECD. The early period until the age of 3 years is critical for the future development of the individuals and the societies. Investment in ECD is an obligation that derives from human rights conventions. Support in early years improves effectiveness and efficiency of the education system. Research has shown that early childhood programs have an effect on preparing children for school and on school outcomes. It is in the early age that influences have an effect on building the essential life skills. ECD is one of the most effective strategies in ensuring social equity, reducing social exclusion and poverty. All these effects yield high return in investment, higher than any other intervention in early years.

The paper is presenting some of the evidence on the effects of poverty on young children and mothers or more precisely it is trying to show the effects of poverty as the main risk to child development- the nature and the scope of the problem, but also pathways in which poverty compromises young child devel-

opment and results in poor child outcomes. It finally suggests effective ways for mediating poverty effects on poor development.

Poverty has detrimental effects on adults, but it is important to emphasize why children are more vulnerable than adults. It is primarily the rapid development of the brain in early years that make children suffer most. Neuroscience research has shown that brain cell connectors (synapses) form rapidly in the first few years of life. The density of synapses peaks at age 3, after which comes a plateau and then a period of elimination, when the density decreases to adult levels (WHO 2008). Whether the intervention is positive or negative it really matters as these have lasting effects. Young child development is especially sensitive to negative effects such as early under nutrition, deprivation of care and of responsive parenting, and ill treatment. If these needs are not met or they are maltreated or abused, the repercussions are often felt into adulthood. It is biological embedding, that the negative impact of poverty is more intense in early childhood and has a greater impact on outcomes than poverty later in life (WHO 2008).

The developmental immaturity described above is making young children especially vulnerable to poverty and associated problems, but it is also that due to specifics of the development in the social and emotional domain which is mediated through relationships that makes the immediate environment of the child play a major role. As the social and emotional development proceeds, children start to develop a sense of self (self-concept and self-efficacy) which on the other hand contributes to the building of their future ability to effect change and achieve goals. This development is best supported through interaction and relationship with parents and caregivers. In circumstances of poverty, parents are exposed to extreme stress which prevents them from active and adequate engagement with their children. This ultimately compromises child development and the realization of human potential. The ability of a child to reach his or her full potential, and become a self-sufficient and successful adult is particularly limited when a family remains consistently poor (Centre for Community Child Health 2009).

Millions of young children around the world suffer from poverty, but those most affected live in Sub-Saharan Africa and South East Asia (Walker et al.

2007). The authors estimate that at least 200 million children under the age of 5 years fail to reach their potential in cognitive and socio emotional development. The number of affected children is calculated based on the prevalence of early childhood stunting and the number of people living in absolute poverty as indicators of poor development. Walker et al. (2007) chose stunting and poverty as indicators of deprivation because they represent multiple biological and psychosocial risks, they are consistently defined across countries and worldwide data on these indicators is available. Knowing the multiple effects of poverty, such as malnutrition, poor child and maternal health, and lack of stimulating home environments and how these risks detrimentally affect their cognitive, motor, and social emotional development, it can be assumed that this number is an underestimation.

How stunting and poverty influence and can be representative indicators of effects on child development? Walker et al. (2007) describes that growth potential and patterns of growth retardation are also similar across countries- faltering begins in utero or soon after birth, it is pronounced in the first 12–18 months, and it continues to around 40 months, after which it levels off . Most of these effects remain through to adulthood. Poverty is measured as percentage of people having an income of less than US$1 per day, adjusted for purchasing power parity by country. Poverty is associated with inadequate food, and poor sanitation and hygiene that lead to increased infections and stunting in children (Walker et al. 2007).

The pathway to poor development described by Walker et al. (2007) starts from the fact that poverty is associated with inadequate food, poor access to water, sanitation and hygiene. Poverty is also associated with poor maternal education, increased maternal stress and depression, and inadequate stimulation in the home. All these factors detrimentally affect child development and poor development on enrolment leads to poor school achievement (see Figure 1). Poverty and socio-cultural context increase young child exposure to biological and psychosocial risks. These risks are cumulative and as they accumulate the development is increasingly compromised.

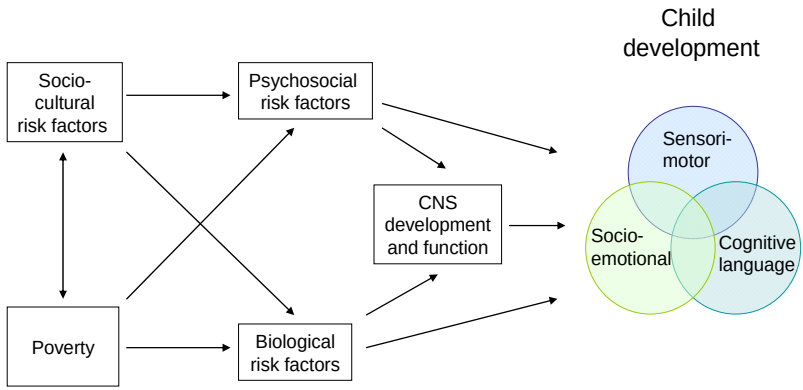


Figure 1: pathways to poor development (Walker et al. 2007)

The biological risk factors include poor maternal nutrition and infections, stunting, anemia and HIV/AIDS. It is estimated that 11% of births in developing countries - are low birth weight or below 2,500 grams, and less than 37 weeks gestation. One third of the children under 5 years of age in developing countries are stunted and there is significant association between stunting at age 2-3 years and cognitive deficits, school achievement and dropout. Large percentage of young children or 46-66% of children less than 4 years of age suffers from anemia and half of these are affected by iron deficiency anemia. HIV/AIDS is the other huge challenge to child development - 4. 2 million children younger than 14 years living with HIV/AIDS or each day 1,800 children become infected with HIV (UNESCO 2007).

Most of the research on the effects of psychosocial risk factors and effects on child development come from the North. Risk factors in this group, like cognitive stimulation/child learning opportunities and caregiver sensitivity and responsivity have strong influence and lasting effects on child development. There are various models that present these effects. Brooks-Gunn (2003) describes the relations between poverty and children's readiness to learn at several levels. Due to poverty families and parents cannot afford stimulating home environment in terms of availability of materials and resources. Poverty affects

the quality of interactions between the parents and children. Families living in poverty cannot afford access to quality of early learning and care outside the home. Poverty affects parental health and community conditions which determine the ability to support children's learning.

According to the investment model - parents cannot afford ECD services, parents cannot afford learning materials, parents cannot afford quality child care and schooling and this causes differences in developmental outcome among middle and high income families (Katz & Redmond 2008). The family risk model describes impact of poverty on relationship and interaction: parental stress from financial pressure lead to emotional deprivations and decreased ability for responsive parenting (Brooks-Gunn 2003).

Early education disadvantages are influenced by socio-economic risk accumulation, informal education and school preparation at home, child rearing beliefs and parenting styles, and bilingualism and language development (EACEA P9 Eurydice 2009). The socio- economic risk accumulation happens due to poverty and includes risk factors such as low income, social status and ethnic/minority status and these risks can have an effect at the level of the child, the family and the community. The most important to emphasize is the parent as a strong mediating factor - in circumstances of poverty parents live in stress about their survival and this causes a shift in focus from the child towards the self. The result is lack of motivation to provide any support to stimulation of the child and harsh parenting.

Informal education and school preparation at home play a crucial role in child development. Through everyday problem solving situations, the parent represents a model of communication and conflict resolution. It is the lack of support to literacy and education as reading and writing that happens in the family as the most important risk factor in creating an educational gap.

When trying to addressing early education disadvantages it is important to consider the existing child rearing beliefs and parenting styles. Beliefs about developmental outcomes - when the child should and is expected to know the numbers, the letters, to read and write, to count and demonstrate different skills - vary across cultures and societies. Across the different countries and cultures mutual roles of parents and teachers vary - some cultures do not see a role of

parent in early stimulation and education and believe the teachers are ultimately responsible for the child development. The parenting styles can also vary from traditional collectivistic - interests of the child are subordinated to the interests of parents and the family associated with authoritarian style; to modern individualistic - focused on the child, authoritative and permissive.

While poverty has similar effects on all children, still poverty in the South is more endemic, widespread and severe. The living conditions of some young children are exceptionally harsh, and they need support and protection simply in order to survive. In these circumstances, resource limited programs have attempted to target the poorest of the poor and identify children most in need of support, however it is extremely difficult to choose anyone for targeting when life is so precarious for the majority of children. Child Poverty and Research Centre (2008) states that assumptions and expectations from the North inevitably spill over in the South but there are roughly three groups of young children who are particularly vulnerable: *Young children whose parents are time poor and absolutely poor*, and do not have the resources to care for them; y*oung children affected by HIV/AIDS* with cumulative effects from the consequence of being an orphan, exposure to sexual exploitation, reluctance within affected communities to foster for young children, psycho-social and physical damage due to stigma; *young children in situation of war and conflict* (witness of deaths of close relations, likely to be impoverished and experiencing poor living conditions, and with poor nutritional status, where women of children refugees act as buffer for their children, themselves likely to be highly distressed, feel helpless and powerless).

In the light of the evidence about the impact of poverty on young child development outcomes, the period of early childhood should be also considered as a critical window of opportunity. Early child development programs can mediate effects of poverty and there is a body of research worldwide from a broad range of programs that has shown these effects. Based on this evidence, several characteristic of successful ECD programs emerge. First and foremost, comprehensive nature of ECD programs, i.e. programs should include a range of services related to health, nutrition, early care and stimulation that address multiple needs of children. Child development is holistic and happens in several do-

mains, thus the programs should focus on supporting these needs at the same time. Focus on disadvantaged children is essential. While ECD programs should in general respond to the needs of all children, they need to also include specific attention and support to the needs of the most marginalized and the disadvantaged. This for instance may relate to the specific cultural or linguistic needs of specific marginalized group of children. ECD programs begin with younger children - as previously described, child development, especially brain development is most rapid in the period from birth and until the age of three and services and programs have to consider this development. Finally, programs should be of sufficient intensity and duration and ensure quality as measured by opportunities for continuous training of staff, opportunities for children to express initiative and explore in their learning environment, opportunities for parents to be involved and these should all be based on the traditional child rearing and evidence-based approaches. Some evidence on what has worked in context of poverty include: early intervention program (Watson & Tully 2008), programs that target families not only children, school based program - extending early intervention to primary school years (Ramey & Ramey 2004); and integrated programs in community settings and home based.

Most of the evidence comes from the North, thus it is important to emphasize that programming has to strongly consider the context. Limited research from the South suggests that early childhood development initiatives in this part of the world should be varied in their target groups, range of interventions, processes and outcomes, and costs. They should also consider the specific context too which profoundly determines expectations of childhood, upbringing and learning, and the values that underpin them (Child Poverty and Research Centre 2008).

Finally based on the knowledge about poverty influences on child development, what works in addressing and mediating the effects of poverty, the benefit of ECD investment and in the light of the commitment and targets set with the Millennium Declaration and Millennium Development Goals (MDGs) by 2015, renewed commitment for ECD is necessary. Again, based on this strong evidence about the contribution and importance of ECD in achieving school success and reduction of poverty, ECD needs to be considered as one of the key

strategies for achieving MDG one on reducing poverty and MDG 2 on achieving universal access to primary education and as such should receive greater attention and support.

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# Strategies and Implementation of the Holistic Approach in Early Childhood Development (ECD)

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> "To the doctor, the child is a typhoid patient; to the playground supervisor, a first baseman; to the teacher, a learner of arithmetic. At times, he may be different things to each of these specialists, but too rarely he is a whole child to any of them."
> White House Conference on Children and Youth, 1930

Over the past decade, programming and policy planning focused on Early Childhood Development (ECD) has been based on affirmative policy attention given to ECD throughout the central and Eastern Europe and Commonwealth of Independent States (CEE/CIS) Region. Policy interest has been guided by extensive body of research showing the importance of quality early experience to short-term child developmental outcomes, as well as to their long term success in school and academic achievement. At the same time, most of the governments in the CEE/CIS Region have recognized the importance of investment in quality ECD services in relation to alleviating some of the negative effects of social disadvantages and ensuring social inclusion. In supporting the youngest children, it is especially important to recognize the role of ECD in achieving basic education for all. Support to young children does not merely refer to establishing preschools or infant classes. It refers to all the activities and interventions that address the needs and rights of young children and help to strengthen the contexts in which they are communicated: the family, the community, and the physical, social, and economic environment.

This paper covers the following subject area:

- Early Childhood Development (ECD) in focus
- Holistic approach to ECD
- Policy responses in support to holistic ECD
- Public policy and possible implementation strategies in ECD

- UNICEF Holistic approach to ECD in a country context (the case of Macedonia)

Findings from desk review of the more recent literature in this field that highlight UNICEF approach to ECD in the CEE/CIS Region will be presented. In addition, the paper will give the most recent insight of the UNICEF country activities undertaken in line of expanding early childhood opportunities for young children in Macedonia.

Early childhood development is the process of child growth and maturation that happens from birth to school entering age. The vision of ECD is broad and includes socialization, education and readiness for school, as well as the provision of basic health care, adequate nutrition and stimulation within a caring environment. Accordingly, this is a time of great importance for cognitive, emotional and psychological development of the child. Interest in early childhood development has dramatically increased in the past years. Research indicates that this is a time of rapid and extensive growth of the brain. In this period, certain kinds of stimulation lead to particular kind of brain cells connection development (Begley 1995). The development of these connection determine children's critical thinking skills, self confidence, problem solving abilities and abilities to cooperate with others (Shonkoff & Phillips 2000).

Researchers, practitioners and politicians seem convinced that the education and the development of young children deserve study and investments in good practice. This growing interest in early child development has certainly been stimulated by international organizations traditionally interested in education, but the Organization for Economic Cooperation and Development (OECD), the International Monetary Fund (IMF) and other institutions concerned with economic development also seem to be increasingly aware of the importance of early childhood development. Due to multidimensional nature of early child development, barriers between separate domains should be overcome in order to address comprehensive nature of child development. This requires an holistic policy approach where education, health, nutrition and social welfare work together in an integrated and inclusive manner in order to provide rich and supportive experience for all children including the most vulnerable.

The term *holistic* addresses the significance of the whole part as opposed to the analysis of each part and can be interpreted within the learning environment as learning which considers the *whole* child. The *whole child* perspective includes the consideration of all developmental areas to be engaged within each interaction and experience provided for the child.

Since children live within a context - family, community, culture, their needs are most effectively addressed in relation to that context. The child's well-being is closely linked to the well-being of the family, specifically to the well-being of the primary caregiver(s). Therefore, support to the family and community can help children; similarly support to children can help the family and community. Since the environment has an impact on children's development, it is also needed to have interventions that make changes in the child's environment. Young children are ready to have successful learning experience in their living context and it is highly connected with having opportunities for positive interaction between the child, parents/caregivers, school practice and community. These deeper understandings of the world around the child include materials she engages with, her home culture and relationships, her community including schools, churches and community recreation programs, as well as media influences. Young children do not view learning and discovery in separate parts, but experience life and the skills throughout each and every interaction in which they encounter.

Historically, the experience of a specialized approach may have been considered advantageous in ensuring more focused attention to separate developmental domains or needs. In the area of child development, however, the holistic approach becomes an issue since it responds to the globally accepted evidence regarding how children develop. In line of the well recognized scientific bases about holistic child development, there is one challenging question that should be taken into account in developing comprehensive ECD policy: holistic view of the child or holistic view of the service provision? The answer is very short and easy: both!

A holistic view of the child provides bases for a more unified approach to early learning that foster key child disposition and attitudes to learning. When children learn they do not learn in pieces. When children engage with the envi-

ronment as well as with peers and adults around them, they learn in holistic ways, through their discoveries which lead to deeper understandings about themselves and others, in all areas of development. In other words - child development is holistic - and cannot be compartmentalized into health, nutrition, education, social, emotional and spiritual variables. All are equally important in a child's life and are developing simultaneously. Progress in one area affects progress in others. Similarly, when something goes wrong in any one of those areas, it has an impact on all the other areas.

On the other hand, ECD community on international as well as national level should create adequate strategies and intervention that enable ECD services to give adequate holistic response to the need of the child and entire family. Full understanding and acknowledge the holistic approach is also an important instrument in enabling childcare professionals to improve young children‘s capacity to develop and learn. In order to provide the best possible early years provision for the developing child, holism does not separate care and education, instead the two are combined to form edu-care.

ECD is the concern of many government sectors, notably the education, social affairs and health sectors. Co-ordination among these sectors in policy development and implementation is essential for ensuring the child's holistic development and the efficient use of government resources. In most countries policies for care and education have developed separately with different system of governance, funding stream and training staff. But a holistic approach is gaining ground as policy makers seek to improve the continuity of early childhood experience and make the most efficient use of public resources.

The term Early Childhood Education and Care (ECEC), used in the OECD Thematic Review, marked a giant step in the history of the field. The term reflects a broad, holistic, integrated and coherent approach. Adding *and* presumes new attitudes and understandings, notably the acknowledgement that all types of services that provide education and care to children under school age, whether coordinated or not, belong to the same field. In sum, there is no point in treating them separately. Another implication of the term is a shared desire to identify, comprehend and overcome the barriers that have previously obstructed unified

action in the field of early childhood - in its philosophy, objectives, management and regulation.

The definition of ECEC contained in the OECD's *Starting Strong* was built on the above premises and is equally suitable for both developed and developing countries. It includes all arrangements for the care and education of children from birth to compulsory school age, regardless of setting, funding or operating hours. It considers related concerns such as family support, gender equality, health, lifelong learning, employment and social integration policies, addressing the field's multiple dimensions. It addresses issues concerning the child's transition from home to ECEC, compulsory school and out-of-school provision. It advocates the close association of care and education with a view to eradicating the historical split between *child care* and *early childhood education*. Above all, it promotes convergent actions across the board – in policy, programs and research. In policy formulation, attention should be given to children's development through a holistic approach to programming.

In a holistic ECD approach, which is based on the Convention on the Rights of the Child (CRC), the child is at the centre of the approach. The family is the most immediate duty-bearer; however the family may lack the necessary means to provide support to the child. Therefore, in a rights-based approach to ECD, the government has the obligation to formulate and implement non-discriminatory and equitable policies and programs, together with non-government partners, to support families, caregivers and community with knowledge, skills and resources for good child care. Adequate access to essential services and commodities must be ensured as well. Governments should take into consideration holistic perspective in developing ECD policies, they have to consider children's health, nutrition, living environment, social and emotional and cognitive development, and protect them from risks. ECD programs at their best are essentially an integrated set of actions for ensuring young children's rights to grow up healthy, well-nourished, and protected from harm, with a sense of identity and self-worth and opportunities for learning. Like the CRC they are uniquely concerned with the whole child. While ECD is indeed about opportunities for learning it is also about the much broader scope of children's rights.

In essence, this means addressing the child's multiple rights within the context of the family and community, using a variety of strategies. This approach gives added value to any activity directed toward young children and their families. The evaluation of single focus programs has demonstrated their limitations and ineffectiveness. The main purpose of developing ECD holistic strategies is providing supportive early learning environment that is conductive to better child development outcomes in achieving full developmental potential. ECD programs at their best are essentially an integrated set of actions for ensuring young children's rights to grow up healthy, well-nourished, and protected from harm, with a sense of identity and self-worth and opportunities for learning. ECD provision is becoming shared responsibility between national governments, local authorities, communities and parents.

Unfortunately, there is no one universal ECD strategy that meets the holistic needs of children worldwide. The policy formulation and developing effective ECD strategies should be based on specific country context, as well as national values and views about the importance of education to human development.

UNICEF is committed to supporting capacity development for governments at the national, sub-national and local levels in areas of policy, research, data collection and analysis, child rights monitoring, cross-sectoral communication and partnerships, and participatory planning processes, particularly in areas that serve as barriers to achieving positive early childhood development and school readiness for all children. In accordance with its mandate, UNICEF pays special attention to the most vulnerable populations with the goal of addressing current disparities and reducing social inequality by breaking the intergenerational transmission of poverty. Effective parental involvement, child developmental outcome oriented interventions and sustainability are the key aspects of ECD programs on local, national and international level.

Too many children worldwide suffer from lack of the essential services that allow them to survive, grow, and participate in their society. The leading principle in developing ECD strategies is to put all above pieces together through following interventions:

1. Support young children's development through providing direct services that address all the developmental needs and rights of children without tradi-

tional split of services. When speaking about holistic approach to service provision for young children, the curriculum, staff training, regulations, funding and supervision should be harmonized to ensure holistic continuity.

2. Educate parents and caregivers: the early years are touch points in parent education. Good parenting habits established in the early years can yield long-term benefits for both children and families. The intersecting needs of infants, young children, and mothers require programs that address these multiple needs. Such programs can help prevent child abuse and other problems rooted in the family.

3. Promote community development: program integration of care and education in early childhood is an entry point for community action and participation. This is helpful to parents, especially the poor, both in linking them to community actions, and in freeing them to work and participate in their community.

4. Strengthen demand: it is important to demystify and translate scientific research into a language understood by families and caregivers. Dissemination of information strategies, raise awareness of the importance of child development activities and creates public demand for them. Children have a right to be cared for and educated. Parents have a right to demand these for their children.

In moving towards greater public recognition of the importance of ECD and integration of ECD sectors, countries have used different approaches in meeting the overall objective in developing effective ECD system, using existing structure and strengths of country ECD context.

UNICEF approach in Macedonia is aimed at improving access to quality early childhood development opportunities for children from 0-6 years and their parents and families, by using the existing kindergarten and ECD community-based network. Since their primary goal is meeting developmental milestones of the children, interventions are oriented toward achieving constant progress for each child. To ensure the achievement of child-related outcomes, the research strongly recommends locating the planning and monitoring of programs for young children within a comprehensive and holistic child development framework.

Early learning and development standards (ELDS) recently developed in Macedonia, represent agreed outcomes for all young children 0-6 years of age

across different developmental domains as crucial for articulating the vision on how services should be organized provided and accountability is to be ensured. They acknowledge multidimensional aspects of child learning and highlight the fact that young children grow physically, socially, emotionally, linguistically, and cognitively at the same time**.**

Child development outcomes are improved when services are provided not only to the children themselves, but to their siblings, parents, caregivers, pre-primary teachers and service providers, who are then empowered with the resources and knowledge they need to provide positive care and support for development.

In supporting ECD integration, UNICEF and counterparts have been working in developing a model of kindergartens as resource centre, in terms of training, provision of diversified activities for children and families and monitoring development and learning outcomes of young children. Successful implementation of early learning standards require effective curriculum, classroom practices, and teaching strategies that connect with young children's interests and abilities, and that promote positive development and learning. Significant expansion of professional development is essential if all early childhood teachers and administrators are to gain the knowledge, skills, and dispositions needed to implement early learning standards. Well-educated, knowledgeable and caring teachers are the key to positive outcomes for children. Efforts to implement early learning standards is being accompanied by in-depth professional development, coaching, and mentoring for teachers, administrators, and teacher educators - not just about the standards themselves but about the appropriate curriculum, teaching strategies, relationships, and assessment tools that together make up a systematic approach to improving outcomes for all children.

Integrative and holistic approach in early childhood programming requires high level of citizen participation and consultation based on a long tradition of participatory democracy, with clear lines established between government, municipalities and people. All stakeholders, including children, parents, community based organizations, private sector and government should be fully involved and have common understanding of comprehensive and holistic ECD programs.

Unfortunately, in countries with different socio-political traditions, a similar directness of consultation and level of participation may be difficult to achieve.

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# The Economic and Social Benefits of Investing in Early Childhood Development

## From Programs to Policies to Build (or Strengthen) ECD Systems: Introducing SABER

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## Introduction and Objectives

Improving the quality of early childhood development (ECD) is at the center of the World Bank's development agenda. In both low- and middle-income countries, the Bank is increasingly supporting - through operational work, policy advice, and analytical activities - efforts to improve ECD around the world. This work is expanding in direct response to the interest expressed by government partners. Based on the convincing findings of the large impacts and cost-effectiveness of investments in ECD, policy makers around the world, together with the international community, now face the challenge of how to devise effective ECD policies to ensure that all children have the opportunity to reach their full potential. In this paper, we introduce an approach to inform this process.

The Human Development Department of the World Bank has initiated a work program called Systems Assessment and Benchmarking Education for Results (SABER) - to develop a tool to characterize education systems, policies, and programs across countries. *SABER-ECD* is one of several topics within SABER, including Teacher Policies, Learning Assessments, Education Finance, and System-wide Governance. SABER will collect, synthesize and disseminate comprehensive information on these areas across countries. This information will enable policy makers and World Bank staff to learn from how other countries address the same policy challenges related to improving education outcomes. In this context, and based on the research evidence of the impact that

early childhood experiences have on life outcomes, ECD programs and policies are of special interest.

In *The Promise of Early Childhood Development for Latin America and the Caribbean*, Vegas and Santibáñez (2010) present key building blocks for countries to achieve comprehensive ECD policies. These building blocks are based on the premise that all countries share the goal of ensuring that children have adequate experiences during early childhood, which will enable them to reach their full potential during childhood, youth, and into adulthood. *SABER-ECD* builds upon this work to present a comprehensive framework for ECD. This framework presents three key ECD policy goals:

- Establishing an Enabling Environment
- Implementing Widely; and,
- Monitoring and Assuring Quality

The framework can be used to benchmark countries' ECD policies within each of the three ECD policy goals. It also presents a comparative lens through which to view countries' ECD policies; through such comparisons, lessons can be drawn from the experiences of other countries and policy options to strengthen ECD at the national and sub-national level can be generated.

In the rest of this paper we present the conceptual framework of *SABER-ECD*, describe the tools which have been developed to complete the benchmarking exercise and the process of benchmarking and, finally, present brief preliminary examples of the application of the framework to several countries.

## Conceptual Framework

### Rationale for Investments in ECD

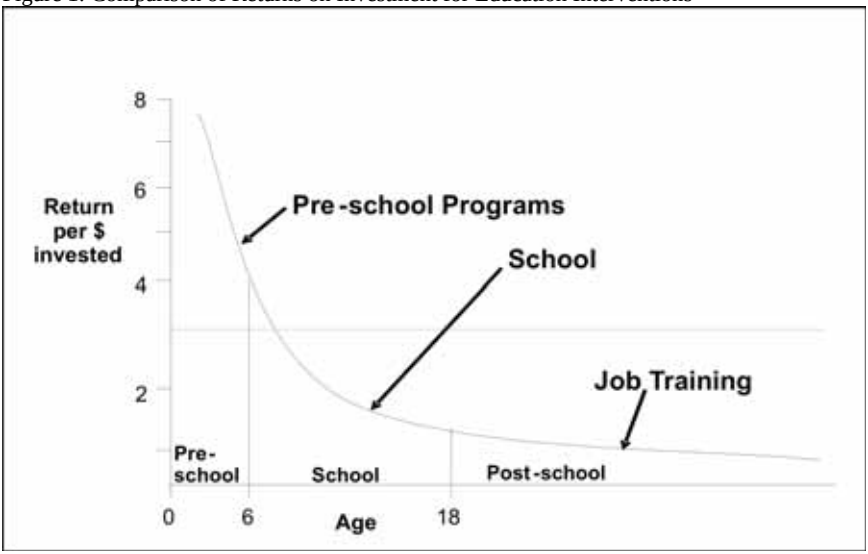
Experiences during the first six years of life affect the development of a child's brain and provide the foundation for all future learning, behaviour, and health (Shonkoff and Phillips 2000). Recent work by Nobel Laureate James Heckman and his colleagues convincingly shows that factors operating during the early childhood years play an important role in the development of skills that determine outcomes later in life (Cunha and Heckman 2007; Heckman 2006; Cunha et al 2005; Carneiro and Heckman 2003). Research has also shown that early childhood interventions can act as an important policy lever to equalize oppor-

tunities for children and reduce the intergenerational grip of poverty and inequality (Heckman 2006).

By the time children reach primary school, gaps in cognitive development are stark, with children from lower socioeconomic backgrounds lagging noticeably behind children from wealthier backgrounds. These gaps in resources, stimulation and opportunities in the early years can have dramatic and lasting consequences for individuals throughout their lives. For many children, the gaps in cognitive development that are apparent at school entry continue to widen with age. Interventions to help children develop in their early years can reduce gaps and improve children's chances of success in later years. A child's family environment is central to her development of skills and ability; hence, early interventions targeted to make up for some early family differences can contribute to reduce early inequalities.

Parental environments and family income available to children during early childhood are far more decisive in promoting human capital and school success than in a child's later years. Investments in ECD have proven highly cost-effective and a wise use of limited government resources. As displayed in Figure 1, investments during the early years yield drastically higher results than those in the primary or secondary school years or beyond.

Figure 1: Comparison of Returns on Investment for Education Interventions




Source: Carneiro and Heckman (2003)

**Definitions**

We refer to Early Childhood Development as the period from when a child is conceived to six years of age (0-6). Three types of outcomes in early childhood are critical for future development in life:

- physical growth and well-being;
- cognitive development; and,
- socio-emotional development.

ECD policies and programs can directly affect these outcomes, and therefore benefit both individuals and societies.

Before continuing, it is also important to distinguish ECD programs from ECD policies. By *programs*, we refer to specific interventions that may vary according to primary objective (e.g. improving physical growth and well-being, fostering cognitive or socio-emotional development), coverage (small scale, universal), and other program characteristics. In contrast, by *policy*, we refer to the regulatory framework and institutional arrangements for service delivery at

the national and/or state level to ensure that a nation's children have access to quality ECD services.

**A Framework to Classify Early Childhood Development Around the World**

Our approach is based on a framework which presents three critical ECD policy goals and follows a series of steps to classify a country's level of development of ECD policies along each goal. Most of the empirical research on ECD has, to date, focused on evaluating the impact of specific ECD programs. As defined above, ECD *programs*, however, differ from ECD *policies*. The analysis presented herein analyzes programs as one component of the process of analyzing a country's overall ECD policy.

Our approach relies on the following three steps, which will be presented in greater detail in subsequent sections of this paper:

1. **Stocktake:** Take stock of the ECD programs and policies that already exist in a specific country.
2. **Analyze:** Use information on ECD programs to classify programs as Sectoral, Cross-Sectoral, Multi-Sectoral and Comprehensive; and use information to evaluate the level of development of ECD policies at the national and/or subnational level along the three critical dimensions of ECD.
3. **Identify Options:** Based on the analysis and international comparisons, using the ECD policy rubric, identify country-specific policy options to strengthen ECD policies to attain the three ECD policy goals.

Our framework presents three core ECD policy goals which all systems should focus on achieving: Establishing an Enabling Environment, Implementing Widely and Monitoring and Assuring Quality.

**Establishing an Enabling Environment**: This goal refers to the existence of an adequate legal and regulatory framework to support early childhood development; the availability of adequate fiscal resources; and the degree of coordination within sectors and across institutions to ensure that services can be delivered effectively.

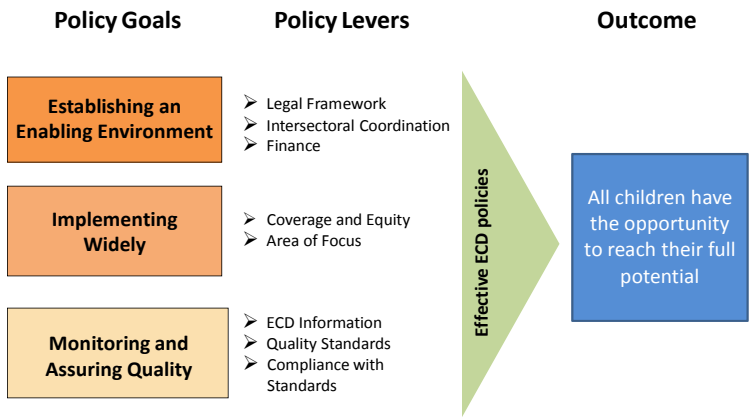
**Implementing Widely**: This goal refers to the extent of coverage (as a share of the eligible population) and gaps in coverage, as well as the specter of programs offered. By definition, a focus on ECD involves (at a minimum) interven-

tions in health, nutrition, education, and social protection. A robust ECD policy should include programs in all essential sectors, intersectoral coordination and high degrees of coverage.

**Monitoring and Assuring Quality:** This goal refers to the development of standards for ECD services, the existence of systems to monitor compliance with those standards, as well as the implementation of systems to monitor ECD outcomes across children.

For each policy goal, based on evidence from impact evaluations, institutional analyses and a benchmarking exercise of top-performing systems, we identify a set of actions, or policy levers, that decision-makers can act upon in order to strengthen ECD. Figure 2 graphically presents the policy levers associated with each ECD policy goal. Taken together, the three policy goals and the eight policy levers comprise a coherent ECD policy system, which should lead to the desired outcome of ensuring that all children have the opportunity to reach their full potential.

Figure 2: Three ECD Policy Goals: From Policy Lever to Outcome




For each of the three policy goals, one can describe levels of development, ranging from less developed (or "latent") to fully developed (or "advanced"). As Table 1 suggests, in an ideal situation, ECD policies in a country would be in

the “advanced” column for all three dimensions. In such an ideal situation, the country would have: (i) a solid legal framework for ECD, sustained financing for attaining ECD goals and a high degree of inter-institutional coordination; (ii) coordinated interventions in all essential ECD sectors and universal coverage in key ECD services such as maternal and child health and preschool education, resulting in integrated services for all young children, some universally provided, others tailored to young children's unique needs; and, (iii) information on ECD outcomes at individual, national, regional and local levels and well-defined quality standards.

Table 1: ECD Policy Dimensions and Levels of Development

| ECD Policy Goal | Level of Development | | | |
|---|---|---|---|---|
| | **Latent** | **Emerging** | **Established** | **Advanced** |
| **Establishing an Enabling Environment** | Legal framework non-existent, ad-hoc financing, few institutions, low within sector coordination, low inter-institutional coordination. | Minimal legal framework, a few programs with sustained financing, low inter-institutional coordination, higher within-sector coordination. | ECD regulations in some sectors, many programs with sustained financing, functioning intra- and inter-institutional coordination. | Developed legal framework for ECD, sustained financing for attaining ECD goals, robust inter-institutional coordination. |
| **Implementing Widely** | Low coverage, pilot programs; some health, nutrition, education, and infant/child protection services, but minimal and without coordination. | Coverage expanding but important gaps remain; some established programs in few sectors; high inequality in access; some health, nutrition, education, and infant/child protection services. | Near-universal coverage or universal in some sectors; established programs in several sectors, low inequality in access; health, nutrition, education, and infant/child protection services well established. | Universal coverage in ECD, with comprehensive strategies across sectors; integrated services for all children, some universally provided, others tailored to young children's unique needs. |

| ECD Policy Goal | Level of Development | | | |
|---|---|---|---|---|
| | **Latent** | **Emerging** | **Established** | **Advanced** |
| **Monitoring and Assuring Quality** | Limited standards exist for the provision of ECD services; only minimal measures of infant & child mortality are reported. | Standards for ECD services exist for at least some sectors, but there is no system to regularly monitor compliance; increased information on ECD outcomes at the national level. | Standards for ECD services exist for most or all sectors; a system is in place to regularly monitor compliance; information on ECD outcomes at national, regional and local levels. | Standards for ECD services exist for most or all sectors; a system is in place to regularly monitor and enforce compliance; information on ECD outcomes at individual, national, regional, and local levels, all young children's individual needs are monitored and met. |

Source: Authors

Table 2 delineates, for each ECD policy goal, the policy levers and how they would be observed at each level of development.

While the “advanced” column represents the ideal, a country with an “established” level of development in the key ECD dimensions indicates a developed policy framework in a majority of sectors, adequate implementation, and multisectoral approaches to ECD.

Table 2: ECD Policy Dimensions, Policy Levers and Levels of Development

| ECD Policy Goals | Policy Levers | Level of Development | | | |
|---|---|---|---|---|---|
| | | LATENT | EMERGING | ESTAB-LISHED | ADVANCED |
| Establishing an Enabling Environment | Legal Framework | non existent | minimal | regulations in some sectors | developed |
| | Coordination | low within sector | high within sector | low inter-institutional | high inter-institutional |
| | Financing | ad hoc | some programs with sustained financing | many programs with sustained financing | sustained for attaining goals |
| Implementing Widely | Coverage & Equity | Low | expanding | universal in some sectors | universal in ECD |
| | Policy Focus (health, nutrition, education & child protection) | some and minimal | some established | well established services | Integrated services universally provided |
| Monitoring and Assuring Quality | ECD Information | Minimal measures | outcomes at national level | outcomes at national, regional, local level | outcomes at national, regional, local & individual level |
| | Quality Standards & Compliance | Limited or no standards | Standards in some sectors | Standards in most sectors, compliance is monitored regularly | Standards in all sectors, compliance is regularly monitored and enforced |

Source: Authors

In a majority of World Bank client countries, an “advanced” level of ECD policy development is attainable in the medium- and long-term. In the meantime, the framework can be used to identify the key dimensions where a country is falling behind this ideal; strategies to address any lagging areas can then be

developed. This exercise is, by definition, country-specific and should be country-led.

## Methodological Approach and Products

### Process

In this section, we expand upon the three steps introduced in Section 2c. and introduce the tools developed to complete the benchmarking exercise. As a reminder, the three steps are the following:

1. **Stocktake:** Take stock of the ECD programs and policies that already exist in a specific country.
2. **Analyze:** Use information on ECD programs to classify programs as Sectoral, Cross-Sectoral, Multi-Sectoral, and Comprehensive; and use information ECD policies to evaluate the level of development of ECD policies at the national and/or subnational level along the three critical dimensions of ECD.
3. **Identify Options:** Based on the analysis and international comparisons, using the ECD policy rubric, identify country-specific policy options to strengthen ECD policies to attain the three ECD policy goals.

The HDNED Team has developed the following four tools to complete the benchmarking process:

- Data collection instrument for ECD programs
- Data collection instrument for ECD policies
- ECD program typology; and,
- ECD policy rubric

All four tools are described in greater detail in Section 3b. Table 3 provides an overview of the process, tools and timeline to carry out a country analysis through SABER-ECD.

Table 3: Early Childhood Development Around the World. Process, Instruments and Timeline

| Step | Process | Tool | Level of Analysis/Lead | Timeline |
|---|---|---|---|---|
| 1) Stocktake | i. Take stock of existing ECD programs<br>ii. Gather information on ECD policies and indicators | i. Data collection instrument for ECD programs<br>ii. Data collection instrument for ECD programs | WB Country Staff/Local Informants | 3 weeks |
| 2) Analyze | i. Classify ECD programs into categories<br>ii. Classify ECD policies | i. ECD program typology<br>ii. ECD policy rubric | HDNED Team | 2-3 weeks |
| 3) Identify Options | Identify country-specific policy options to strengthen ECD policies | Based on ECD policy rubric, and international comparisons | HDNED Team and WB Country Staff | 2 weeks |

**Detailed Description of Tools**

In order to gather information (Step 1), two tools have been designed :

(1) *Data collection instrument for ECD programs* – this is a 2-page questionnaire, designed to collect information on existing ECD interventions in a country. The instrument is designed to collect information on both public and private interventions and programs at different stages of development, as well as programs in the different sectors which comprise ECD.

(2) *Data collection instrument for ECD policies* – this is a longer questionnaire (about 40 pages) designed to collect in-depth information on ECD policies in a country. Table 4 presents key sample questions for each of the three policy goals.

Table 4: Sample of questions for each ECD policy goal

| *ECD Policy Goal* | *Key sample questions* |
|---|---|
| **Establishing an Enabling Environment** | Legal Framework |
| | • According to law, what ECD services are provided free of charge?<br>• Are there any established tax breaks or financial incentives for parents of young children?<br>• Has your country established national child protection laws? |
| | Intersectoral Coordination |
| | • What steps have been taken to establish an ECD authority?<br>• Does your country have an ECD strategy? If so, please provide the name, year of creation, years of coverage and sectors covered. |
| | Financing |
| | • What percentage of the total Government budget was allocated to ECD programming in the following sectors: health, nutrition, education, parenting special needs, anti-poverty, child protection, other?<br>• What is the annual operating budget for the established ECD agency? |
| **Implementing Widely** | Coverage & Equity |
| | • At the national level, what percentage of pregnant women are in need of prenatal nutritional support? At the national level, what percentage of pregnant women in need of nutritional support receive nutritional support? |
| | Policy Focus |
| | • Please describe nutrition efforts in your country. For example: supplements, vitamin and fortified food programs, Vitamin A coverage, iodine coverage or iron deficiency. |
| **Monitoring and Quality Assurance** | ECD Information |
| | • Can individual children's access to ECD services be tracked? |
| | Quality Standards |
| | • Are there established standards for ECD healthcare delivery?<br>• Are early childhood education centers inspected regularly? |

In order to analyze gathered information, two tools have been designed, which are described below.

*ECD program typology*. Once adequate information has been gathered on existing ECD programs within each country, programs can be characterized according to a set of main attributes – this step is useful in order to compare the wide variety of ECD programs that can exist in a country. Key characteristics of ECD interventions include:

(1) *Primary policy objective*: Each ECD program should have a clear policy objective. Some examples include: getting young children school ready; providing nutritional supplementation to a specific population; ensuring parents receive parenting education to facilitate cognitive stimulation of infants.

(2) *Brief description*: For each program, it is useful to present a brief description of its main characteristics.

(3) *Focus area/intervention mechanism*: There are several important areas of focus of ECD interventions, including: health, nutrition, education, parenting practices and poverty alleviation. Within these areas, there are also distinct intervention mechanisms, such as milk or micronutrient supplements, early childhood care in centers and/or at home, preschool education and parenting education. An important dimension for classifying ECD programs is therefore the area of focus of the intervention.

(4) *Coverage/access*: Programs vary in the extent to which various populations can access them, ranging from very low coverage to universal access.

(5) *Institutional arrangements*: Understanding the underlying institutional arrangements for the provision of ECD services is important. This includes policy setting, oversight (including monitoring and evaluation) and provision of services.

(6) *Financing*: The funding available for ECD as well as the specific financing mechanisms employed to channel funds to programs and providers are important determinants of access, quality, equity and efficiency. Documenting the financing of ECD programs is also important for evaluating cost-effectiveness of alternative interventions.

(7) *Service providers*: Various government agencies at several levels of government (national, state, local), private sector providers and community or-

ganizations can all be service providers. For each program, it is important to understand who is responsible for service provision.

(8) *Quality assurance mechanisms*: Research evidence indicates the important role that quality of ECD services plays in the effects of ECD programs on an individual's life outcomes. Understanding how different programs ensure quality is therefore critical. Quality assurance mechanisms range from establishing standards for service delivery, to supporting providers in meeting the standards and enforcing compliance.

(9) *Challenges for going to scale and improving service delivery:* An important goal is for effective programs to be scaled up to reach all those young children who are eligible. This dimension refers to the challenges for going to scale and improving the quality of service delivery. Identifying these challenges is a necessary step toward then devising strategies to address them.

These characteristics are used to develop a categorization of ECD programs into four groups based on their primary policy objective, as follows:

- *Sectoral*: Provide a specific service to some or all children;
- *Cross-Sectoral*: Provide some ECD services to some groups of children (can be specifically targeted to specific populations);
- *Multi-Sectoral*: Give children equal opportunities to reach their full potential in life; and,
- *Comprehensive*: Ensure that all children reach their full potential in life.

Sectoral programs are typically independent interventions in specific sectors such as health, or education, often led by government agencies or NGOs with low inter-institutional coordination. Examples of these include preschool education and nutritional supplements.

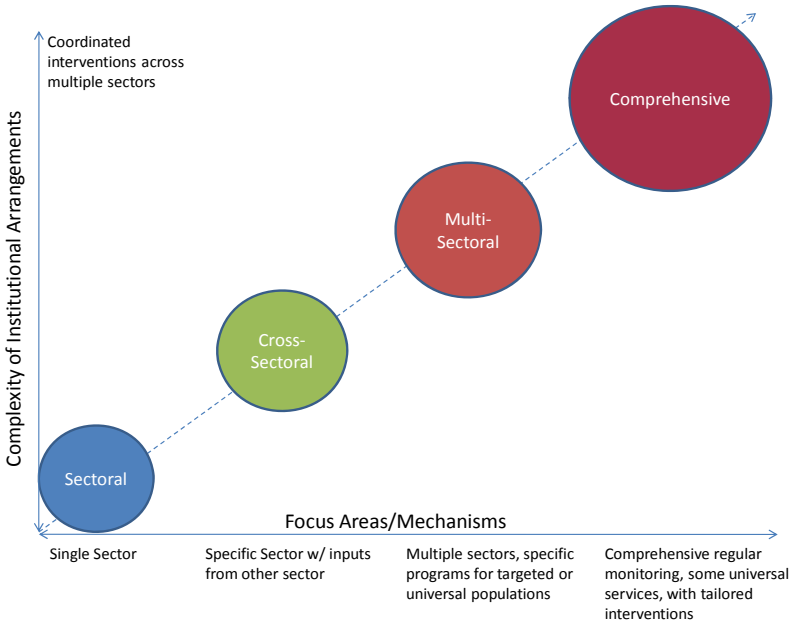
Cross-Sectoral programs also are usually independent interventions in specific sectors but with some component from another sector, often led by government agencies or NGOs. Some cross-sectoral programs involve large-scale interventions with strong political leadership; they are often targeted to vulnerable populations but require relatively low inter-agency coordination or integration across sectoral policies. Examples of these include school feeding programs.

Multi-Sectoral programs involve the implementation of multiple interventions in a coordinated way, where the focus is reaching children with systematic interventions during early childhood. They can vary in the degree of coverage, some being targeted to vulnerable populations while others are universal in coverage. They require a high degree of inter-agency coordination.

Comprehensive programs are those with a comprehensive approach to ECD involving multi-sectoral interventions but tailored to each child, following individual ECD growth trajectories to ensure that all children receive adequate multi-sectoral support as needed. They require a high degree of inter-agency coordination and integration across sectoral policies.

Figure 1 graphically describes how these four categories of ECD programs differ in terms of focus areas and institutional arrangements.

Figure 1: Categories of ECD Programs: Focus Areas and Institutional Arrangements




Source: Authors

It is important to note that these categories represent a continuum of possible ECD interventions and that, therefore, some programs may not fall exactly within the description of one category. In these cases, we use our best judgment to classify them into one of the four categories, but recognize that improved information may affect this classification.[1]

*ECD policy classification rubric*: In order to systematically and accurately compare ECD policy across different countries, we have developed an ECD policy rubric, based on the three ECD policy goals: establishing an enabling environment, implementing widely and monitoring and assuring quality. This rubric is a tool to collect data on ECD programs and policies within a country and determine the extent to which the country has developed – or is developing – adequate ECD policies to ensure all children have the opportunity to reach their full potential. The data collected through the two questionnaires is inputted into the rubric, along with additional secondary data collected from relevant sources (such as UNICEF, World Health Organization or the Human Development Report). It is important to balance the primary data we collect with quantitative secondary data about ECD in the country. It is also important to gather a sense of what is actually occurring on the ground. For this reason, many questions in this data collection instrument seek to assess the extent to which *in law* rules that guide ECD are reflected in practice. For example, the requirements for establishing an ECD center in a country may be very strict, but in reality, only a minor proportion of operating centers may fulfill these requirements. The rubric is designed to accommodate all of these important considerations to present a balanced report on ECD policy in each country.

## Conclusion

There is no single path to achieve an advanced level of ECD policy and different systems will place varying levels of emphasis on each policy goal and lever. SABER - Early Childhood Development is designed to present client countries with a framework and tools to consider policy actions to create a holistic ECD policy environment in which all children have the opportunity to reach their full potential.

## Acknowledgements

This document was produced by the core team of the *Early Childhood Development Policies Around the World* initiative, which includes Emiliana Vegas (Task Team Leader and Lead Economist, The World Bank); Veronica Silva Villalobos (Consultant, The World Bank); and Amanda Epstein (Consultant, The World Bank). Clark Matthews (Consultant) provided excellent research assistance.

The team is grateful to Robin Horn (Manager, Education Team, Human Development Department) and Elizabeth King (Director, Education Unit, Human Development Department), who provided overall guidance.

Colleagues across the World Bank provided feedback that contributed to improve the initiative. The team is especially grateful for valuable suggestions received, at various stages of this work, from: Wendy Cunningham; Peter Holland; Sophie Naudeau; Agustina Paglayan; Carla Paredes; Cristobal Ridao-Cano; and Alexandria Valerio.

All remaining errors are the sole responsibility of the authors.

## Abbreviations

SABER Benchmarking Education Systems for Results

ECD Early Childhood Development

HDNED Education Unit, Human Development Department, The World Bank

## Note

1 For instance, an evaluation of program implementation and impact may imply that a specific sectoral program moves up from one category to another. As a result, some programs may be transitioning from, for example, "sectoral" to "cross-sectoral".

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# Early Child Development in Developing Countries: The Role of Nutrition and Stimulation

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## Introduction

Millions of children under five years in developing countries do not attain their developmental potential due to poverty and associated risk factors including nutritional deficits and inadequate stimulation and care-giver child interaction. Poor development in the early years results in children entering formal schooling at a substantial disadvantage. This has long term implications as ability on school entry predicts school progress both in number of grades attained and learning achieved per grade thus leading to low levels of educational and economic attainment in adulthood. Furthermore, poor parental education is linked to poor health, nutrition and development of the offspring. Thus poor early child development is a step in the pathway of the transmission of poverty from one generation to the next.

In this chapter we review the impact of nutrition and stimulation on early child development and longer term cognitive and behavioural outcomes.

## Nutrition

### Intra Uterine Growth Restriction

Fifteen percent of children in developing countries are born with low birth weight (LBW) (UNICEF 2008). LBW in developing countries is primarily due to intrauterine growth restriction (IUGR) associated with undernutrition among women prior to pregnancy and during pregnancy (Kramer 2003).

There is consistent evidence that infants born at term with IUGR have lower developmental levels up to ages 2-3 years (Walker et al. 2007). Term SGA

(small for gestational age) infants in Guatemala had lower cognitive and verbal scores up to age three years than normal birth weight (NBW) infants (Gorman & Pollitt 1992,Villar et al. 1984) and term LBW infants in Brazil and Jamaica had lower developmental test scores compared with normal birth weight infants (Grantham-McGregor et al. 1998, Walker et al. 2004). A more recent Guatemalan study, showed associations between birth size adjusted for gestational age and development at ages 6 and 24 months which were independent of postnatal growth (Kuklina et al. 2006).

There is also some information on the longer term effects of term LBW. In a Brazilian study, birth weight unadjusted for gestational age was a significant predictor of IQ at age five years (Santos et al. 2008). Combined analyses of five cohorts showed that an increase of one standard deviation in birth weight (unadjusted for gestational age) was associated with 0.22 years increase in highest school grade achieved (Martorell et al. 2010). However, the contribution of prematurity cannot be estimated in these studies. A large study in Taiwan, Province of China, using national data bases reported small but significant effects of term LBW on academic achievement at age fifteen years (Wang et al. 2008).

In contrast, follow-up of the term Guatemalan infants described above found no significant differences at four or five years or in reasoning ability and educational achievement in adolescence (Pollitt et al. 1991, Gorman & Pollitt 1992). There were no significant effects of term LBW on IQ at age six years in Jamaica (Walker et al. 2010) or at age eight years in a study in Brazil (Emond et al. 2006). No differences in parent reported behavior between LBW and NBW children were found in either study or in self reported behavior in a cohort of children at age 12 years in South Africa (Sabet et al. 2009).

IUGR is associated with lower developmental levels in early childhood. Associations with later outcomes are less consistent and more evidence is needed of the longer term effects in developing countries.

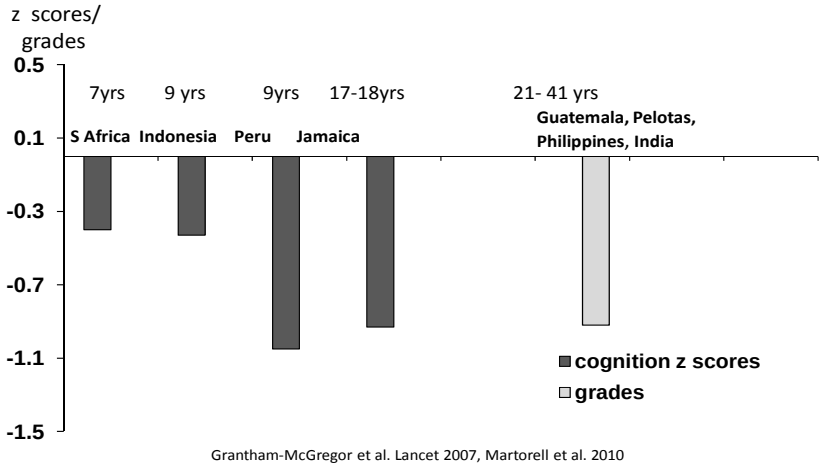
**Stunting**

Stunting (height-for-age < - 2 SD of reference values) is estimated to affect 34% of children under five years in developing countries (UNICEF State of the World's Children 2010). There is substantial evidence of an association between stunting in the first three years and poor child development (Grantham-

McGregor et al. 2007). However, undernourished children generally come from disadvantaged backgrounds and it is likely that other factors such as poverty, poor housing, poor health care, low levels of parental education and unstimulating home environments confound the relationship between undernutrition and child development. Longitudinal studies are more useful as the temporal relationship between undernutrition and development can be established. There are several longitudinal studies of the association of stunting by age two or three years with later development. Early height for age was associated with cognitive and/or language ability at five years of age in studies from Brazil (Santos et al. 2008), Vietnam, (Le Thuc 2009), India (Helmers & Patnam 2009), and Peru (Sanchez 2009). After controlling for social background covariates, stunting was associated with deficits in later childhood in IQ (Walker et al. 2000, Berkman et al. 2002), nonverbal intelligence (Martorell et al. 1992, Mendez & Adair 1999) other cognitive tests, school achievement and conduct disorder (Martorell et al. 1992, Chang et al. 2002, Walker et al. 2005). Stunting was also associated with poor schooling outcomes such as fewer grades achieved (Martorell et al. 1992) increased dropout (Daniels & Adair 2004, Walker et al. 2005), late age of enrolment and grades attained at 17 years (Alderman 2006). In Jamaica, children stunted before age 2 years had poorer psychological functioning at 17 years than non-stunted comparisons (Walker et al. 2007) and in the Philippines, height at 2 years was related to the likelihood of having formal work at 20 to 22 years of age (Carba 2009).

Early growth seems especially important. Post natal growth to 6 or 24 months was related to Guatemalan children's mental and motor development, but growth from 24 to 36 months was not related to development at 36 months (Kuklina et al. 2006). Pooled analyses of data from five on-going longitudinal studies found one SD of growth in weight from birth to 24 months was associated with increased schooling (0.43 years) whereas growth from two to four years had a negligible effect (Martorell et al. 2010).

Figure 1: Deficits in standard scores in later cognition or grades attained associated with stunting (height/age < -2SD) before three years of age from long term follow-up studies (Grantham-McGregor et al 2007; Martorell et al 2010)




## Macronutrient Supplementation

Several randomized trials have been reported in which food supplements were given in an attempt to improve children's nutritional status and development. These have included studies designed to prevent undernutrition in high risk populations (Waber et al. 1981, Pollitt et al. 1993) and studies in which supplements were given to undernourished children (Grantham-McGregor et al. 1991, Husaini et al. 1991, Pollitt et al. 2000). Supplementation led to benefits in children's developmental levels during the intervention with gains of 6-13 points in supplemented groups compared with controls. There is thus fairly consistent evidence of concurrent benefits for child development.

There is less information on whether benefits of supplementation are sustained. Limited benefits were found at age 8 years from supplementation of short duration given to undernourished children (Pollitt et al. 1997). In the Jamaican study, supplementation beginning at age 12 to 24 months in stunted children produced a small growth response and benefits to development were

not sustained, whereas another group receiving stimulation showed sustained benefits (Walker et al. 2005). The most substantial sustained benefits have been found in the Guatemalan study among participants whose mothers were supplemented in pregnancy and who were supplemented at least until age two years (Pollitt et al. 1993). This trial has reported long term benefits to reading comprehension and reasoning at a mean age of 32 years in participants who supplemented from birth to 24 months but not those where supplementation began later (Stein et al. 2008). Also men supplemented throughout the first 3 years but not women or those beginning later earned higher hourly wages (Hoddinot 2008).

In conclusion, there is consistent evidence linking early childhood growth retardation with concurrent and long term cognitive deficits and poorer educational outcomes and some evidence indicating effects on behaviour and later psychological functioning. Improving children's dietary intake to prevent or reduce undernutrition benefits current development and may have long term benefits particularly if supplementation is preventative and provided before age two years. *It is unlikely that nutritional supplementation alone will allow undernourished children to catch up in cognition to their well nourished peers and they require improvements to their environment.*

**Iron Deficiency**

An estimated 47% of preschool children are anemic globally and 50 to 60 % of them are iron deficient (Black et al. 2008). In some less developed countries the prevalence of anaemia is over 60% (Ahmed 2000). There is ample evidence from animal research that iron deficiency causes changes to the brain structure and neurochemistry. Research with children has also shown changes to brain function. Many reviews (e.g. Grantham-McGregor & Ani, 2001, Sachdev et al. 2005, Lozoff, 2007) have shown that young children with IDA (iron-deficiency anemia) generally have poorer cognitive, motor and behavioural development than non-anemic peers that continues through out childhood. The longest follow up of children with IDA before 2 years of age showed that the cognitive deficits persisted at 19 years and were worse in children from poor backgrounds compared with those from more affluent backgrounds (Lozoff et al. 2006), suggesting that poor children are more vulnerable to IDA. However, IDA is associated

with many other socio-economic disadvantages that may independently affect children's development and randomized treatment trials with iron are necessary to infer a causal relationship.

Short term iron treatment studies of less than two months have generally had no benefits. Below we briefly summarize the literature on double blind randomized trials with longer term treatment. We focus only on studies with clear evidence that iron treatment benefited the iron status of the children and the placebo group remained more anemic or iron deficient. We found six randomized longer trials with children who were anemic or had mixed iron status some with IDA and some iron replete (Stoltzfus et al. 2001, Idjradinata et al. 1993, Aukett 1986, Lind et al. 2004, Olney et al. 2006, Black et al. 200). Two showed benefits in motor and mental or language development (Stoltzfus 2001, Idjradinata et al. 1993), two showed benefits to motor development only (Lind et al. 2004, Olney et al. 2006). One study reported beneficial effects on motor development from iron and zinc combined but only a non-significant benefit from iron alone. One found no significant benefits (Aukett et al. 1986). We found two preventive randomized trials with non-anemic children (Freil et al. 2003, Moffatt et al. 1994), both found beneficial effects on motor but not mental development.

In conclusion, whereas eight trials looked at motor development and six showed benefits, seven trials looked at mental/language development and only two found benefits. There appears to be sufficient evidence showing that iron deficiency anemia affects motor development but the effects on mental development are less consistent and the data are insufficient to come to conclusions. It remains possible that the detrimental effects of iron deficiency on cognitive development in children under two years is irreversible without improving the environment. One study has shown psychosocial intervention benefits cognition in children with IDA (Lozoff et al. 2010).

### Multiple Micronutrients

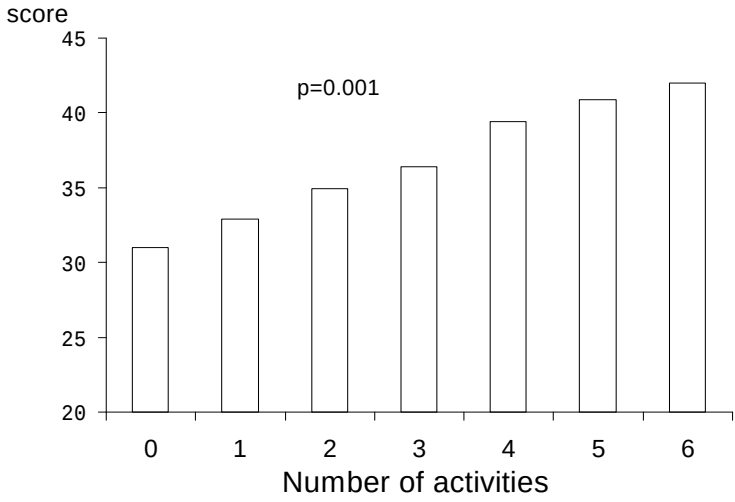
In addition to iron many other micronutrients are deficient in children in developing countries including zinc, vitamins A, B12, D, E and riboflavin (Allen et al. 2009) as well as iodine in some regions. Recently there has been interest in using multiple micronutrients (Mns) rather than single nutrient for supplementation.

Defining multiple micronutrients (Mns) as three or more micronutrients, we found six randomized trials of Mn supplementation or fortification in young children (Faber et al. 2005, Olney et al. 2006, Black et al. 2004, Abdu-Afarwuah et al. 2007, Dhingra et al. 2004, Katz et al. 2010). The findings were generally similar to those of iron supplementation trials. Four of the six studies showed benefits to motor development and of the two studies that looked at mental development neither showed benefits. It is difficult to determine which Mn was responsible for the motor benefits and whether Mns are more effective than iron or iron and zinc alone in improving motor development.

**Stimulation**

Walker and colleagues (2007) identified inadequate cognitive stimulation as an urgent modifiable risk factor for young children in developing countries. Stimulation in the home has been shown to be an independent predictor of children's mental development in several studies from developing countries (Hamadani et al. 2010, Santos et al. 2008), particulary for children who are more vulnerable or disadvantaged (Barros et al. 2009, Grantham-McGregor et al. 1998). For example, in Bangladesh, mothers' reports of the number of play activities they did with their child was associated with children's language development at 18 months in a dose response manner (Hamadani et al. 2010) (see Figure 2). A similar association was found between number of play materials and child language.

Figure 2: Language comprehension score at 18 months by number of play activities




**Early Stimulation Interventions to Improve Child Development**

There is convincing evidence that interventions which increase cognitive stimulation by increasing the learning opportunities provided for young children in developing countries have significant benefits to child development including cognition and behaviour over the short term (Baker-Henningham & Lopez-Boo 2010, Engle et al. 2007,Walker et al. 2007). Benefits have been found for children exposed to a range of biological and contextual risks including poverty (Klein & Rye 2004, Powell & Grantham-McGregor 1989), institutionalisation (The St Petersburg-USA Orphanage Team 2008), stunting (Grantham-McGregor et al. 1991), severe malnutrition (Grantham-McGregor et al. 1987, Nahar et al. 2009), low birth weight (Walker et al. 2004), pre-term birth (Bao et al. 1999), iron-deficiency anemia (Lozoff et al. 2010), and HIV positive status (Potterton et al. 2010).

The most widely evaluated approach for providing stimulation for children aged birth to three in developing countries is through home visiting pro-

grammes. Home visits are usually conducted by paraprofessional staff and the focus of the intervention is on both the mother and the child. Mother's active involvement is promoted and home-made books and toys and common materials in the home are used to engage the child in play. These programmes generally lead to benefits to children's mental development of between 0.3 to 1 standard deviation. In a Jamaican study, home visiting was integrated into the regular services provided through primary health care services. Community health aides were given a caseload of between four to six children in addition to their usual duties, and they conducted home visits over one year. Marked benefits were found to children's development indicating that this approach is both feasible and effective (Powell et al. 2004). However, the approach has yet to be adopted by the Jamaican government and given the limited number of children that can be reached, this is likely to be most appropriate for children at particulary high risk.

Other approaches to improving young children's learning opportunities during the first few years of life include individual counseling sessions at clinics, parent training through group sessions and centre-based care, for example, provision of high quality day care. Each of these approaches has been shown to be effective in promoting child development over the short term in one or more studies (Engle et al. 2007, Walker 2011). The approach used will depend on the availability of existing services into which the interventions can be integrated, the availability of personnel including staff to implement the intervention and supervisory staff, the costs involved and the needs of participants in the programme. For example, day care provision will be most appropriate in contexts in which a significant proportion of disadvantaged children have mothers who work.

### Integrated Approaches

Risk factors for poor development usually covary and disadvantaged children encounter multiple risks to their development including poor health and nutrition in addition to inadequate stimulation. Integrated child development programmes target multiple risks and have shown benefits to various measures of child development (Armecin et al. 2006, Behrman et al. 2003). One non-randomised trial in Vietnam showed that adding a stimulation component at

preschool age to an earlier nutritional intervention benefited stunted children more than non-stunted children suggesting that nutritionally vulnerable children may benefit more than adequately nourished children from these interventions (Watanabe et al 2005). A study with stunted children in Jamaica showed that nutritional supplementation and stimulation had independent benefits to child development and the effects were additive (Grantham-McGregor et al. 1991). Only children receiving both supplementation and stimulation had developmental levels similar to a non-stunted group of children at the end of the intervention. In Bangladesh, moderately to severely malnourished children attending feeding centers in the community participated in a home-visiting intervention for one year. The children failed to improve in nutritional status over the year and the benefits from stimulation were small and this small effect was attributed to poor nutritional status (Hamadani et al. 2006). These studies suggest that integrated programmes are particularly important for children with nutritional deficiencies.

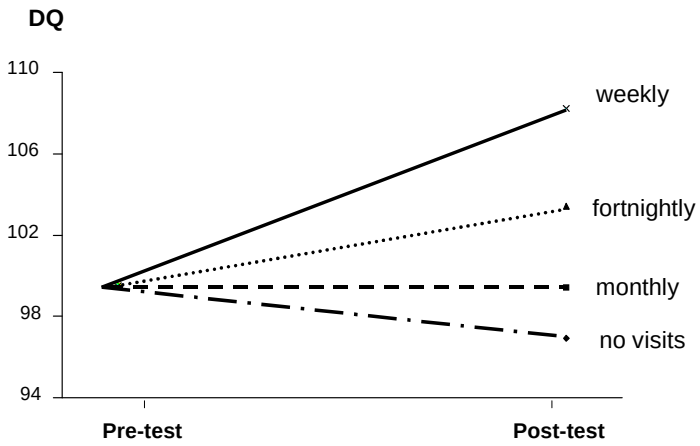
**Sustainability of Benefits**

There is also some evidence that benefits from early stimulation are sustained into later childhood and adolescence. For example, in Jamaica, early stimulation with stunted children involving two years of home-visiting by paraprofessionals in early childhood led to significant benefits to children's cognition, school achievement and mental health at age 17-18 years (Walker et al. 2005, 2006). In another Jamaican study, benefits to child IQ were found in adolescence (eleven years after the end of the intervention) for severely undernourished children who had received stimulation in hospital and three years of home visits (Grantham-McGregor et al. 1994).

**Factors Affecting the Effectiveness of Stimulation Interventions**

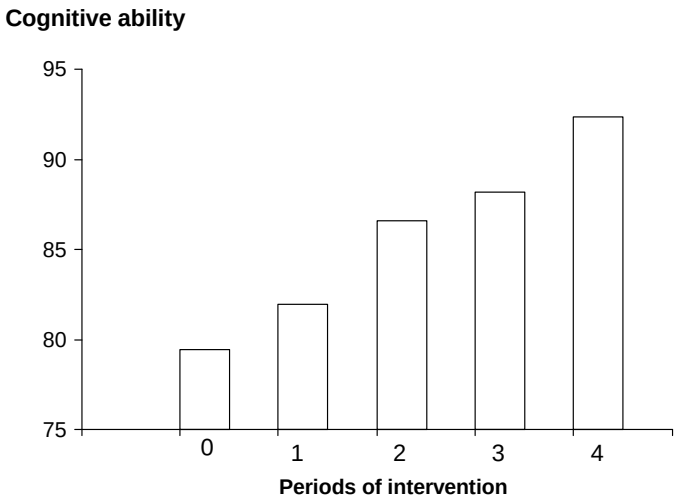
There is limited data to guide decisions relating to the optimal intensity, duration and age at start for improving child outcomes. In Jamaica, weekly home visiting led to larger gains in child mental development than fortnightly visits which in turn were more effective than monthly visits (Powell & Grantham-McGregor 1989) (Figure 3).

Figure 3: Effects of visiting frequency on development quotients (DQs) of disadvantaged Jamaican children




In Columbia, a combined health, nutrition and stimulation centre-based intervention with undernourished children led to increased cognitive gains with increased duration (McKay et al. 1978) (Figure 4). However, it was not possible to separate the age of beginning from the duration. Few studies have investigated the effect of child age but there is some evidence that younger children may benefit more (Armecin et al. 2006). The majority of studies investigating the effect of early stimulation on child development have been efficacy studies and in these studies close attention was paid to the quality of intervention delivery including adequate preparation of intervention staff and ongoing monitoring and supervision. There is less information on how these interventions can be taken to scale while maintaining effectiveness; however, there are examples of large scale programmes that have shown substantial benefits to child development (e.g. Armecin et al. 2006). It is likely that close attention to the quality of intervention delivery is critical to its effectiveness.

Figure 4: Cognitive ability at age 7 years by duration of intervention in Columbia (McKay et al. 1978)




**Benefits to Mothers**

Benefits from early stimulation programmes have also been found for maternal outcomes including increases in mothers' knowledge of child development, parenting practices and stimulation provided in the home (e.g. Powell et al. 2004), improvements in mothers' status within the family (Kagitcibasi et al. 2001) and reductions in maternal depressive symptoms (Cooper et al. 2002, 2009, Baker-Henningham et al. 2005). These benefits are likely to contribute to improved child development and may be one mechanism through which gains to child development are sustained.

## Conclusion

In conclusion, it is clearly established that in developing countries millions of children are failing to reach their potential in development and that early childhood interventions are effective and can have sustained benefits. Where re-

sources are limited we need to explore innovative approaches to integrating early childhood interventions into existing health and education services, or other points of contact such as faith groups and women's groups as this is likely to be most cost effective. We presently lack sufficient political will to ensure investment of the required resources. It is therefore important to urgently and vigorously advocate for the resources to mount interventions on a large scale. The use of carefully collected evaluation data should assist in this advocacy and in the design of programs.

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# Early Childhood Development Screening

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Save the Children

The importance of early childhood development (ECD) and stimulation continues to gain recognition as the most-effective and cost-efficient time to ensure that all children develop to their full potential. In 1992, Robert Myers pointed out that after decades of concentrated effort to combat disease and malnutrition in the majority world, 12 of 13 infants born in these societies will survive to age one. This is a result of our success at providing vaccinations, immunizations and adequate sanitary conditions so as to prolong life. However, despite having met some basic physiological needs, many children continue to live in less than adequate developmental environments. In order for children and societies to reach their full potential, we must address new issues such as how to help children obtain their right to a robust life, including access to and success in school.

Most young children in the majority world have little exposure to print, early learning opportunities or materials that prepare a child for school. Many of their parents have had limited or poor experiences with school and as a result are less familiar with child rearing practices that are linked with school success. Data spotlights that exposure to parenting support interventions and early childhood care and development programs (ECCD) can improve children's cognitive and social-emotional development and school readiness. ECCD programs consistently show children are more likely to enroll in and complete primary school when compared to a similar set of children who have not participated in an ECCD program (Save the Children 2010; Martinez 2011). Nevertheless the percentage of children with access to formal early learning opportunities remains extremely low. Only 17% of children in Sub-Saharan Africa, 19% of Middle Eastern children and 29% of young children in Central Asia have been exposed to formal early learning activities (UNESCO 2011).

This paper will summarize the concept of *early childhood development*, offer a rationale for why there needs to be dramatic increase in funding for ECCD programs, and finally describe two essential elements that should be part of an

early childhood development program: 1) early developmental screening; and 2) exposing parents to skills that will support their young children's development. In a recent study, 23% of children in low- and middle-income countries were identified with disabilities. Children who access ECCD programs are more likely to be exposed to activities that mediate developmental delay. Offering early screening and detection within routine ECCD programs (e.g. community-based child care centers, formal government pre-schools, and alternate ECCD programs) children should be exposed to health, vision and developmental screening. In each distinct ECCD project, children should receive health, vision and developmental screenings. The earlier we identify delays increases the probability that a young child will be exposed to interventions that mitigate or even stop more serious problems later in life.

Parents - especially mothers - (and/or other primary caregivers) continue to be the child's first and continuous *teacher*. During the developmental trajectory of children, parents are key players in a child's language, social and cognitive development. There is extensive evidence showing that parents of developmentally delayed and high-risk children can be taught to be sensitive to their child's behavioral cues for interaction and how to respond to the child's needs. Studies from Asia and Africa have shown that interventions that enhance early mother-child interactions and support child development result in improved cognitive and psychosocial development as well as child health (cited in Walker, et al. 2011). In addition, parents and other caregivers benefit from mother-child group interventions and/or parent training on child development and adaptive ways to support children with delays.

The recent two-part *Lancet* series *Child Development 1 and 2* (Walker, et al. 2011; Engle, et al. 2011) states that children in low- and middle-income countries are exposed to multiple risk factors during the early years of life (e.g. extreme poverty, violence, malnutrition, infectious diseases, HIV, developmental disabilities, and other factors) which results in physical change in their brain structure and function. As a result, these children fail to reach their developmental potential. However, research shows that there are protective factors that help reduce the impact of risk factors, such as exposure to child stimulation, respon-

sive caregiving and similar ECCD interventions, and enhance a young child's developmental trajectory.

## Background: What is Early Childhood Care and Development (ECCD)?

Early Childhood Development (ECD) is the gradual emergence and *development* of sensory-motor, cognitive, language, and social-emotional capacities in young children (prenatal-8 years). It refers not only to what is happening within the child, but also to the *care* that children require in order to thrive. For a child to develop and learn in a healthy and normal way, it is important not only to meet the basic needs of food, health, protection, but also to meet the basic needs for interaction and stimulation, affection, security, and learning through exploration and discovery. The breadth of ECCD results in the need to integrate health, nutrition, protection, legal rights and early stimulation for young children and their families. Although there is a vast amount of literature that documents the nuances of early child development, Save the Children and similar development agencies have adopted a comprehensive, holistic ECCD Framework and examines early childhood development and *school readiness* across four primary developmental dimensions: 1) physical well-being and motor development; 2) social and emotional development; 3) language development; and 4) cognition and general knowledge. Though presented separately below for the sake of clarity, the dimensions are closely linked.

- *Physical Well-Being and Motor Development:* A strong body of research links maternal and child health to performance in school. We know that conditions such as very low birth weight and poor nutrition affect a child's preparedness for school. Basic health care like immunizations and exclusive breastfeeding until six months predict a child's readiness for school and life. Early childhood educators also emphasize the importance of optimal motor development in children, from large motor movements that occur while playing to small motor work (i.e. holding a crayon or putting together puzzles).
- *Social and Emotional Development:* This dimension serves as the foundation for relationships and a sense of personal well-being that comes

from stable interactions in children's early lives and interactions. Important conditions of social and emotional development include emotional support and secure relationships that enable a child to develop its self-confidence and ability to function as a member of a group.

- *Language Development*: Language empowers children to participate in both the cognitive and affective components of educational programs. Experience with language, in both written and oral form, provides children with the tools to interact with others and to represent their thoughts, feelings, and experiences. Early exposure to language and the practice of elaborating descriptions of a child’s experience is predictive of vocabulary in primary school.
- *Cognition and General Knowledge*: A foundation for later learning is provided when children have opportunities to interact with individuals and materials and, as a result, are encouraged to learn from their surroundings. Children's transitions to primary school are eased when children have experience with a variety of play-oriented, exploratory activities, and when their early school experiences continue these activities.

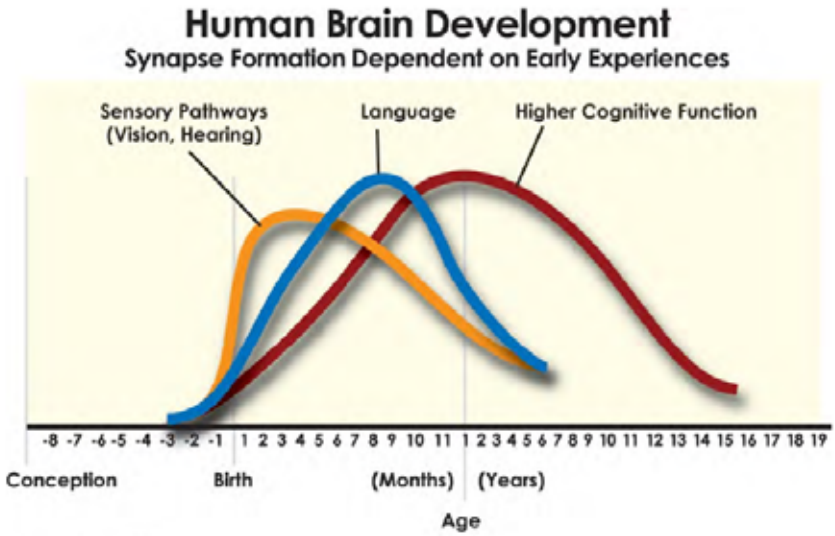
In addition to ensuring that children start school ready to learn, Save the Children recognizes that schools need to review how they welcome children into their context. For example, schools should work with children and parents before children enroll in primary school. Research has shown that children begin to make sense of their environment, and those around them, much earlier than originally thought. Early caregiver-infant interactions and early learning environments frame how children experience the world. Lastly, communities need to be safe and secure for children and community leaders need to generate local and national ECCD policies that support prenatal care, nutrition, physical activity and health care for children to ensure that children arrive at school with healthy minds and bodies.

## Rationale: Why invest in Early Childhood Development?

Brain development is most rapid and vulnerable from conception to five years. During the early years a child develops all the basic brain and physiological structures upon which later growth, development and learning depend. Graph 1

below shows when synapses proliferate in utero and during the first years of life.

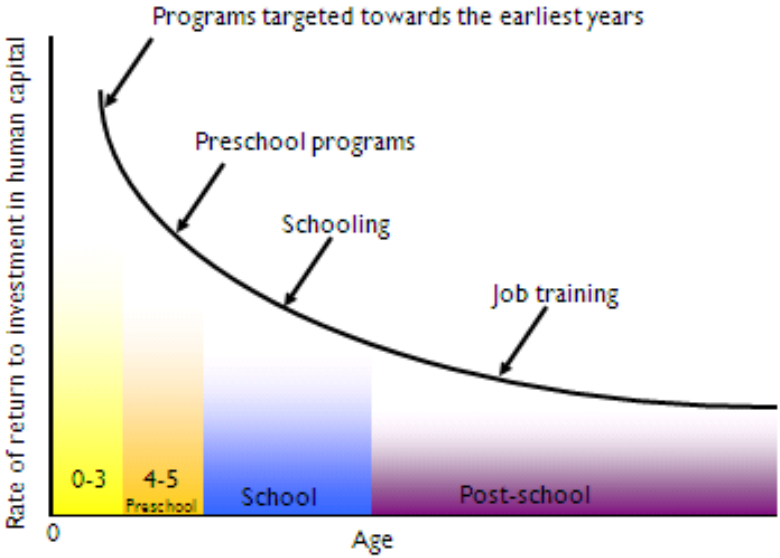
Graph 1: Human Brain Development: Synapse Formation Dependent on Early Experiences




Source: Nelson (2000)

Beyond developmental theory, economic research now shows that investing in the early years of life offers the greatest return on investment in human capital. Investments in programs that offer young children quality health, nutrition and stimulation offer societies tremendous economic returns. Children who participate in quality ECCD programs have better health, education and economic outcomes later in life (Engle, et al. 2011; Walker, et al. 2011). Part of this impact can be explained by the fact that preventive programs tend to cost less than remedial or restorative programs.

Graph 2: Early Interventions are more cost effective than at other ages




Source: Based on Heckman an Masterov, 2007

## Essential Elements for ECCD Programming: Screening and Parenting

Two critical contributions of ECCD programs are: 1) Children who enroll in ECCD programs are more likely to be screened for developmental delays. The children who manifest delays during the early screenings are more likely to access early intervention programs that can retard and/or reverse poor developmental trajectories; and 2) Parents (or caregivers) of developmentally delayed and high-risk infants and youngsters can be taught to increase systematically their responsiveness and consistency in reading their child's behavior cues – resulting in improvements in child outcomes (Kaiser & Hancock 2003). As governments and local communities increase their investment in ECCD programming, we urge them to intentionally include valid developmental screening and link children to available resources. If/when there are insufficient services accessible to children and their families, ECCD programs need to document the

incidence of distinct developmental delays and should create local programs that address delays and advocate for governments to offer appropriate services.

Children who are exposed to several risk factors stemming from extreme and prolonged poverty plus the added risk factor of having a developmental delay are in greatest need to access early intervention services. The recent *Lancet* child development series highlights how ECCD and parenting programs protect children from the elevated risk factors. The cumulative effect of multiple risk factors (e.g. malnutrition, poverty, developmental delay, HIV) during the early years have shown to have increased negative effects on young children later in life and result in limiting their access to full potential.

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# Mother and Child Health in Developing Countries Solution Approaches: the Work of *Doctors for Developing Countries*

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## Introduction

The health of millions of children in developing countries is affected and their age-appropriate development impaired by malnutrition, poverty-related illnesses and harmful environmental conditions.

The mother - above all in the first two years - plays a decisive role in the health and development of the child, as during this time it is still largely dependent on her. Only a healthy, psychologically stable mother, with sufficient resources at her disposal, can adequately help and support her child. That is why the health, status and self-esteem of the mother play a decisive role in the psychological and physical growth of her child.

If we wish to improve the health of children in our projects on a lasting basis we have to work out comprehensive approaches that start with the mother.

In the following I would first like to address some of the problems that affect children in their development. Afterwards I will present some solution approaches which we *Doctors for Developing Countries* implement in our projects and in which cooperation with partner organisations plays an important role.

## Malnutrition

Nutritional deficiencies in the first years of life have a negative influence on the cognitive and physical development of a child and often reduce its chances of economic and social success in later life.

In addition, nutritional deficiencies weaken the immune system of the child and render it as a result susceptible to infectious diseases, which are also the main cause of death in the first five years of life. Many children would survive pneumonia, measles or malaria if they were adequately fed. Diarrhoea in malnourished children occurs significantly more often and is more serious than for

healthy children in the same age. It leads to the loss of further important nutrients in the infant body, exacerbating the negative effect of malnutrition on its health and age-appropriate development.

More than 13 million children per year are born underweight and have a poorer foundation for healthy development from the very beginning. The main cause is malnutrition of the mother, whose body is not able to provide for the child sufficiently during pregnancy. Delayed child development already begins during pregnancy. Mother and child suffer equally from the consequences of insufficient nourishment. If the child cannot repair the nutritional deficiencies in its later development the downward spiral continues into the next generation when the underweight girl becomes a mother.


Fig. 1 Malnutrition starts at conception

Alongside the insufficient amount of food it is primarily the lack of vitamins, trace elements and minerals that affects the health of mother and child and impairs child development.

Iron deficiency has to come at the top of the list. In developing countries 45% of all women in child-bearing age suffer from iron deficiency (WHO). The problem worsens during pregnancy as now the child consumes the mother's iron reserves. An increased risk of suffering a premature or still birth, an underweight new-born baby and delayed development in early childhood are the direct consequences. In addition, pre-existent iron deficiency increases the mother's risk of dying during or after giving birth.

Iron deficiency is mainly diet related. Poor populations in developing countries nourish themselves chiefly from rice, maize and vegetables. Only the very few can regularly afford iron-rich foods such as meat or fish. In addition, worms settle in the intestines of the many people forced to live without adequate access to clean water and sanitation. The worms feed on valuable nutrients, including iron, from the intestines of humans and exacerbate the deficiency.

A sufficient supply of iron is absolutely necessary for physical fitness and for the healthy development of a child, as oxygen can only be made available to the body when it is combined with iron. It is therefore not surprising that the productivity of a country could be increased by 20% if the iron deficiency in the population could be corrected.

Further important nutritional components that are often missing from the diet of poor people are vitamin A, vitamin D and calcium. *Vitamin A* is present in yellow and red fruits as well as in certain oils; vitamin A deficiency leads to a massive weakening of the immune system with consequences that have already been described and, in addition, to night blindness, destruction of the cornea and ultimately blindness.

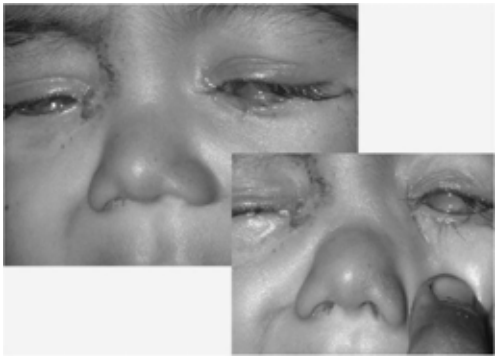

Fig. 2: Ocular changes linked to vitamin A deficiency

Vitamin A is distributed by health programmes in almost all developing countries to children under five. It is important therefore to make access to these health services possible for all mothers and to encourage them to bring their children along regularly.

The body gets its calcium mainly from milk products, whereas vitamin D is activated in the skin by sunlight and facilitates the incorporation of calcium into the bones. Calcium and vitamin D deficiency therefore have a negative influence on the skeletal system.

In the case of mothers the skeleton becomes so weak that movement becomes difficult and painful (osteomalacia). Caring for a small child can as a result become an unendurable burden. In the case of children, deficiency leads to a deformation of the bones and to a retarded and restricted ability to walk and move (rickets).

Fig. 3: Changes to the bones linked to vitamin D deficiency

## Tuberculosis, Epidemic of the Poor

Approximately one million children worldwide are infected with tuberculosis, the majority in developing countries. The figure is probably considerably higher as tuberculosis is very difficult to diagnose in small children. The younger the

child, the greater the chances are that after an infection by tuberculosis bacteria it will become ill with tuberculosis and die. The source of infection for young children is mainly family members, often the mother.

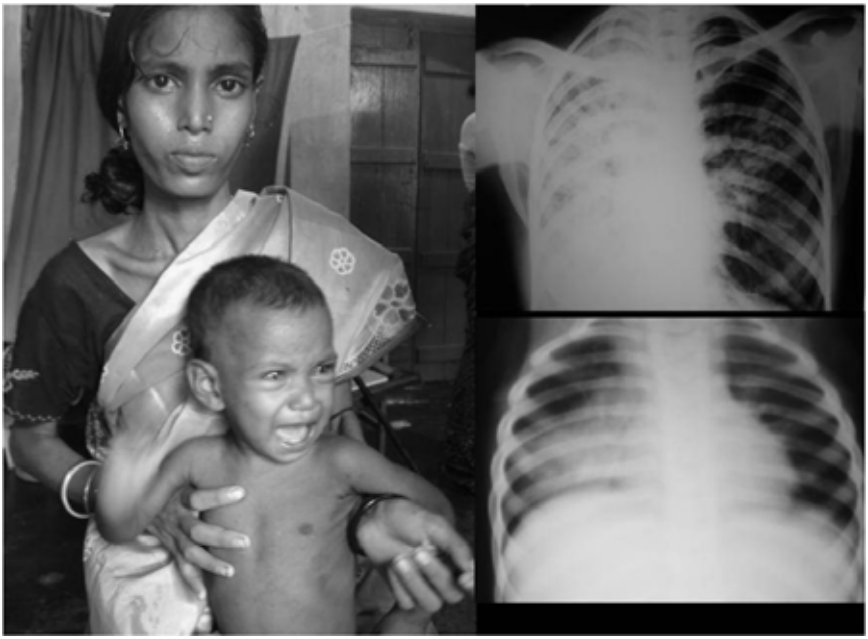

Fig. 4: Tuberculosis in mother and child

Tuberculosis most often affects the lungs. It leads to coughing, loss of weight and developmental delay. Only when it is recognised and treated in time can permanent damage be prevented. Tuberculosis however, can also affect other organs in the human body, for example, the bones. In particular, spinal tuberculosis leads to serious deformation and can through spinal cord compression lead to paralysis. The result can be lifelong disability.

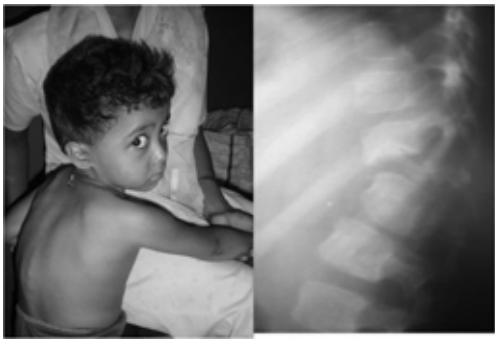

Fig. 5: Spinal tuberculosis

## Educationally and Psychologically Disadvantaged Mothers

A lack of access to adequate nutrition and illnesses (such as tuberculosis or AIDS) are not the only causes of malnutrition in children. The mother's ignorance and lack of experience often play an important role and lead to a child suffering from serious nutritional deficiencies even though access to adequate supplies of food is possible.

It is especially in the poorer urban areas where young women live separated from their family of origin and their familiar village community. Whereas in the villages there are women who can answer the many questions to do with the health, upbringing and support of a child, in the urban slums the women often live isolated lives. Due to a lack of language skills, insufficient school education and cultural restrictions they have little access to the necessary information. One also has to take into account that in many developing countries young women at marriage are no older than 15 and already mothers of several children by 18.

In addition, conditions in the city slums are often marked by violence, insecurity and fear, an environment in other words, which is neither for the women nor for the children friendly or conducive to development. In addition, violence in marriage is a common occurrence and often enough the woman's only choice is to submit unconditionally to a husband with violent tendencies or to be abandoned by him, which means that she then receives no support at all anymore and is solely responsible for the economic survival of the family. We *Doctors for Developing Countries* experience many women in our projects who work in

clothing factories, at markets or in households while their children are left to themselves and the oldest sibling is responsible for the smaller children. The consequences for the health and development of the children are not difficult to imagine.

Many times women are broken by the inhuman conditions; they sink into lethargy, resignation and unhappiness. No strength remains for the care and support of the children even for absolute necessities.

Fig. 6 Mothers overburdened

## Solution Approaches

### Health Care

Access to reliable health care for mother and child is a decisive milestone on the way to improving the health of mothers and children. The health care has to be reachable and has to offer preventative measures (such as vaccination, vitamin A administration and deworming) as well as the diagnosis and treatment of illnesses at affordable prices. Seriously undernourished children require a careful dietary build up in special centres.

In cooperation with state programmes access to treatment for tuberculosis or to medicines against AIDS has to be ensured. Patient-friendly services and confidence-building measures have to be planned in such a way that even mothers without any school education feel spoken to.

*Doctors for Developing Countries* is implementing this concept in its projects. Together with local professionals and translators, German doctors are working in the poor districts of various cities offering free health services (including diagnosis and medicines) to the people. *Doctors for Developing Countries* is working in India, Bangladesh, Kenya, Sierra Leone, Nicaragua and in the Philippines.

Fig. 7: Doctors for Developing Countries

Children suffering from tuberculosis are treated in cooperation with local specialist doctors and it is quite impressive to experience how a child can recover from this serious illness.

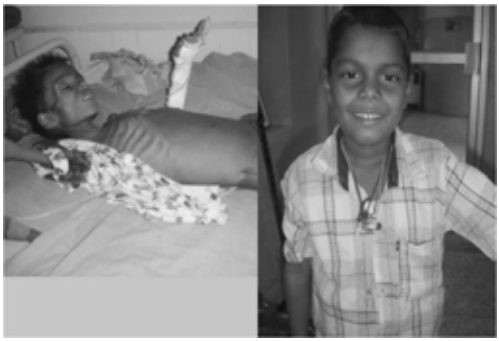

Fig. 8: Child before and after treatment for TB

## Measures for Empowering Women

In order to improve the health of mothers and children in poor districts on a lasting basis it needs however much more than health programmes. Only through the reliable cooperation of the mothers will we be able to improve the health of the children in the long-term. To a comprehensive approach whose goal is to improve the health of mothers and children belong therefore measures for empowering women such as women's self-help groups, advisory services for mothers and nursing mothers, training courses and income-creating measures for women.

The goal is to promote the self-awareness, sense of responsibility, competence and knowledge of mothers and to support them in putting all these into practice for their children.

Much malnutrition could be prevented if mothers could learn from the experience of others. Much violence could be prevented if women had other experienced, trained women as contact persons in their neighbourhood. Many crisis situations in a family, whether through the illness or death of the breadwinner, could be averted if for example several women pooled their savings.

Fig. 9: Women's self-help group

## Work at the Local Authority Level

In most developing countries women are insufficiently involved in decision-making processes in the family and at the local authority level.

Projects aiming to promote the health of mothers and children on a lasting basis also have to focus on this aspect and increase local authority awareness of the needs of mothers and children. This is a difficult and lengthy task which of course can only be carried out by competent local organisations.

In several cultures the mother-in-law plays a very important role; once they are convinced of the correctness of a piece of advice they will assist their daughters-in-law in putting it into practise. Sometimes it will be possible to have talks with teachers, mayors or church officials who have an influence on local structures.

Important points that can only be solved in cooperation with local authorities are: a supply of clean drinking water, access to adequate sanitation and school education for all children (girls and boys).

Fig. 10: Community meeting

**Cooperation among Different Aid Organisations**

Every organisation has its particular focus, experience and competence. For such a complex issue as the promotion of mother and child health, it is only reasonable that the different organisations get together in order to cooperate.

*Doctors for Developing Countries* is working together in the large slums of Calcutta with *Kindernothilfe*. Here *Doctors for Developing Countries* is carrying out health care for mothers and children, preventative work (vaccinations, de-worming and administration of vitally important vitamins), prenatal care as

well as the treatment of sick children on a children's ward or in a children's tuberculosis hospital, seriously ill mothers are treated and cared for medically in other inpatient facilities.

A centre for women has been set up in cooperation with an Indian partner organisation which offers women a one-year manual skills training, lessons in reading, writing and arithmetic and professional advice.

In cooperation with *Kindernothilfe*, special doctors' consultation times could be arranged for malnourished children and as well, high-quality, calorie-rich food provided for seriously undernourished children.

Furthermore, the work for the women was intensified and extended as well as work started with local and urban district authorities with the goal of providing information and building awareness.

## Credits

Fig. 1: Missionsärztliches Institut Würzburg

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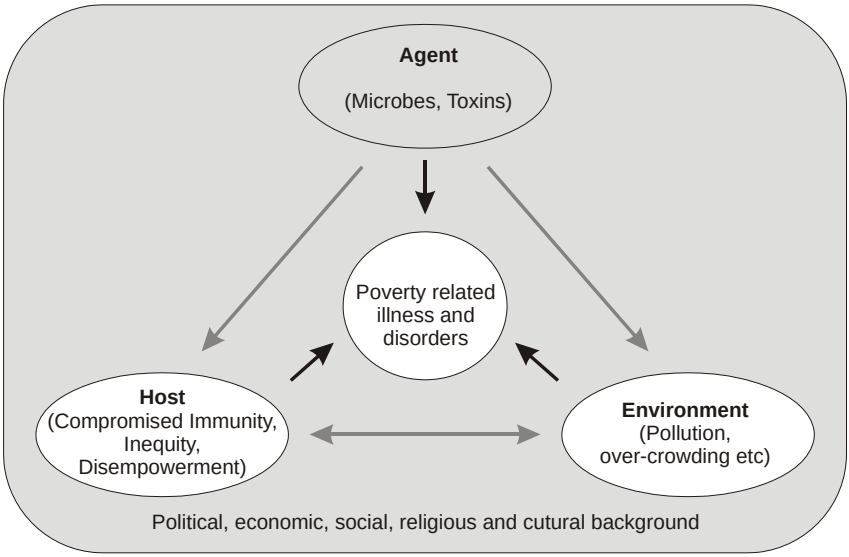
# Poverty-Related Diseases and Early Childhood Development

*Dr. Bhoomikumar Jegannathan*
Caritas Cambodia

## Poverty-Related Illnesses and Early Childhood Development

The child may be the *father of the man*, but the newborn child is dependent on parents, immediate family, the community and the country into which she or he is born in order to survive and to attain his/her full potential. The perils during the early years of life are enormous particularly for the children born amidst impoverished settings in low- and middle-income countries. Even in high-income countries, children who experience poverty during early childhood are more at risk from asthma and other chronic illnesses[1]. When adequate nurture and care is provided during the early years, children have fewer illnesses, are more likely to survive and develop adequate cognitive, language, emotional and social skills[2]. Children who receive early intervention and care do well in school and as adolescents have better self-esteem and have a greater chance of becoming creative and productive members of the society.

The complex interaction between poverty, malnutrition, lowered immunity and recurrent infections has been reported and documented time and again[3] and the challenge is to break this vicious cycle.

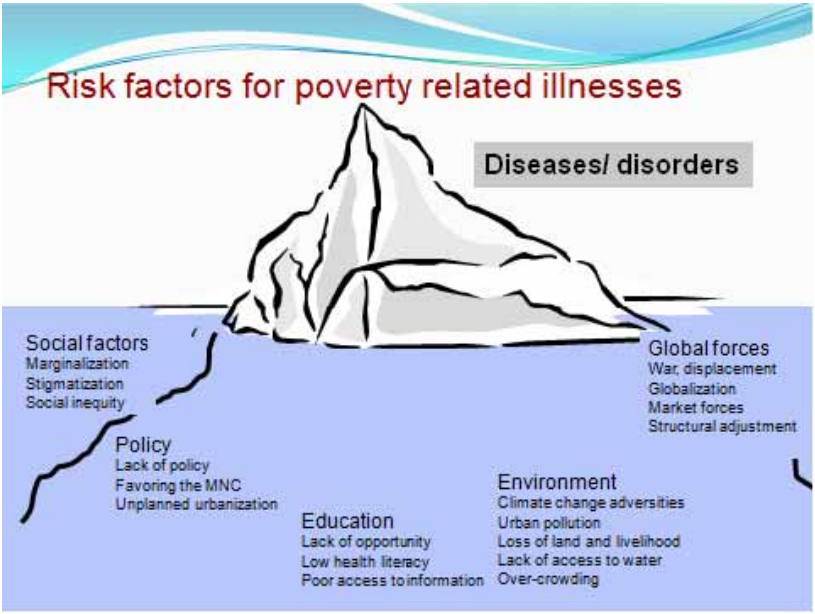



By adequate and appropriate community-based interventions it is possible to break the cycles of poverty, disease and their ramifications that affect millions of children in low- and middle-income countries. But tragically, every year, around 132 million infants in the world are blocked in their developmental trajectory, devoid of health, nutrition and protection that they need to survive, grow, develop and learn. Out of 100 children born in 2010, 30 will suffer from malnutrition in their first five years of life, 26 will not be immunized, 19 will lack access to safe drinking water and 40 to adequate sanitation and 17 will never go to school[4]. In low- and middle-income countries, every fourth child lives in abject poverty, resulting in compromised early childhood development and the situation is more complex in post-conflict countries such as Cambodia.

## Poverty and Illness in Cambodia, a Post Conflict Country

Cambodia suffered from the spill-over of the Vietnam War followed by the genocidal regime of the Khmer Rouge from 1975 to 1979 during which about two million people died to war, starvation and sickness. During the 1980s and 1990s, more than a million people lived in the refugee camps along the Cambo-

dia-Thai border and they reported the following: 56% lacked food/water, 44% lacked shelter, 28% lacked medical care, 24% reported brainwashing, and 8% reported torture. More than 80% reported poor health, 55% felt depressed and 15% had posttraumatic stress disorder[5]. The levels of trauma were unprecedented and the impact of war on the health of the women and children of Cambodia continues to this day. War, trauma and poverty have made deleterious impacts on the mental and physical health of children. *Overburdened, traumatized and time-poor families* neither have the information nor time to spend in stimulating play during the key developmental phase of children, resulting in compromised/delayed cognitive development[6].




Poverty-related illnesses and disorders are the tip of the iceberg and the war and poverty nexus can have long-term social, economic and political repercussions, depriving the children of the nurturing and trustful environment conducive for early child development and growth. Caritas Cambodia has carefully

taken the above factors into consideration while planning the comprehensive community-based intervention.

## Primary Prevention of Poverty-Related Diseases/Disorders. Community Participatory Programme in Cambodia

### Dialogic Partnership with Pregnant and Lactating Mothers

Cambodia has the highest maternal mortality rate (460/10,000) in the region, as only 22% of the pregnant women in rural Cambodia have access to trained midwives during delivery[7]. Poor nutrition and ill health among Cambodian mothers lead to low birth weight, putting their offspring at greater risk of developmental delay, malnutrition, disabilities and decreased child survival[8]. It is important to give children a good start in life, which begins during pregnancy. The community outreach team at the Center for Child and Adolescent Mental Health (Caritas-CCAMH), a unit of Caritas Cambodia, has incorporated the following components[9] into the comprehensive community-based programme through continuing dialogue and partnership with pregnant and lactating mothers.

1. Enhancement of a mother's antenatal care to have a healthy baby
2. Enhancement of a child's development early in life by reducing illness, improving cognitive, social and emotional development
3. The education of parents and/or caregivers in better parenting, health, and hygiene practices

### Participatory Health Communication for Behavior Change

A lack of access to water and sanitation has a deleterious impact on child health mainly due to increased waterborne infections and infestations[10]. Simple hand washing before eating and after going to the toilet can prevent disabling and debilitating illnesses such as polio, diarrhea, dysentery, cholera, typhoid and worm infestation, all poverty-related (poor environment) illnesses. The Caritas-CCAMH team has introduced hand-washing and nail-clipping as a *fun activity* among children, encouraging them to change their behavior.

## Poverty-Related Disorders and Cost-Effective Interventions

Poverty-related disorders such as micro-nutrient deficiency disorders (iodine, iron and vitamin A) are equally if not more important than acute illnesses[11]. Time-poor and exhausted mothers involved in life-sustaining food and water-collecting activity do not have energy left at the end of the day for quality interaction with their children. Keeping this in mind, the Caritas CCAMH team actively involves the volunteers for child development (VCD) in the villages to promote the following:

1. Adequate stimulation and learning opportunities through games/ activities involving all the children (both abled and differently abled) in the village
2. Use of iodized salt among pregnant and lactating mothers
3. Home garden to improve iron status among women and children

## Community Partnership and Evidenced-Based Intervention

The Caritas-CCAMH team, being part of the Caritas Cambodia community development team, has gained experience in community organization and establishing volunteer-based groups in the villages to address poverty-related health issues. Implementing evidence-based early childhood programmes in active participation and collaboration with the community[12] has enabled to achieve the following in the communities where Caritas-CCAMH is currently working to promote inclusive development:

- Access to basic medical care for children and pregnant women
- Intensive home visitation for vulnerable mothers
- High-quality early education programmes
- Direct support to families experiencing distress
- Services for children experiencing toxic stress
- Work-based income supplements for poor families
- Policies to reduce the level of neurotoxins in the environment

Though there is tremendous enthusiasm in the community for active involvement and partnership, it is a challenge for the community to sustain the same level and commitment to address the issues related to early childhood development when the Caritas-CCAMH team withdraws from the area.

We share the vision of the eminent social pediatrician Prof. David Morley that the needs of children cannot be postponed and have to be met here and now, and we shall continue to strive for that!

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## Summary of Workshop Results

# Consequences of Poverty Factors for Early Child Health and Development. Presentation of a Rural Community Based Health Program for Prevention and Treatment of Children's Diseases and Development Disorders in Cambodia

Dr. Bhoomikumar Jegannathan presented a rural community based health program focussing on children’s diseases and development disorders in a number of remote villages in Cambodia with little or no access to institutionalised health care facilities. Crucial elements of this community based program are periodical visits of interdisciplinary professional teams to the villages and training of volunteers and so-called health messengers actually living in the villages and therefore close to the target populations. In this way the volunteers are enabled to visit and counsel families and identify health problems and development disorders in children as early as possible, as well as to train parents and families to respond adequately and effectively themselves to the needs of the children and to facilitate referral of the affected children to health facilities if necessary. This program is part of a general inclusive community development program of Caritas Cambodia which also targets poverty alleviation.

After the presentation of the Cambodian example the discussion of the participants of this workshop focussed on reflection around two main question complexes:

1. *Where do we stand in our own work? / What are the problems we are dealing with?*

The following major challenges were identified:

- A community based, decentralised approach requires participation which creates ownership and can make a program sustainable in the long run. However, this bottom-up approach requires time and patience. How can donors be made to understand the need for time?

- Often there is antagonism or even conflict between Government authorities and NGOs regarding awareness for needs and priority of objectives and policies. How can lobbying of NGOs become successful?
- It is often difficult to maintain the commitment of volunteers (high fluctuation rate) which poses a major problem for the sustainability of community based programs.
- Attitudes of non-inclusiveness sometimes also characterize the relationship between the different groups of persons with disabilities. And suspicions and stigma regarding disability or certain types of disability are not only poverty-related, for example due to lack of education, but exist on all levels of society. How can such attitudes be changed?
-

2. *What is needed for successful programs? / Demands or recommendations?*

The following elements for successful programs were collected:

- Awareness raising on reasons of poverty plus measures for poverty alleviation, for example supports for income generation (micro credit schemes/revolving funds) linked with self-help groups.
- Basic training and continuous upgrading of knowledge and skills for volunteers on the grassroots level, as an element of participation that can enhance motivation and sense of responsibility.
- Continuous upgrading training of professional staff going to the field.
- Further important factors to create ownership and ensure sustainability on the community level are: targeting of community leaders as key persons; pay attention to the role of religious groups and organisations and involve them as well; needs assessments on the community level; develop accessible formats or concepts of inclusive participation of all people with disabilities.
- For political and financial sustainability: cooperation of government authorities and NGOs is absolutely necessary; public-private partnerships should be strived for.

*Christine Wegner-Schneider*
Caritas international
Workshop Facilitator

# The “Mo.Ki. Monheim for Children“ (Monheim für Kinder) Pilot Project

*Annette Berg*
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The Arbeiterwohlfahrt’s (AWO) regional association and the town of Monheim - located in the Lower Rhine area in the State of North Rhine Westfalia – have developed a model project on *Child Poverty – Overcoming and Avoiding Consequences of Poverty for Children and Families*. The *Institut für Sozialarbeit und Sozialpädagogik e.V.* (ISS) is providing scientific support and process evaluation. The model project is funded by the *Landschaftsverband Rheinland* in Cologne.

In the starting phase of the project the analysis of key problems has been crucial, taking into account approaches for preventing child and family poverty in the district named *Berliner Viertel* in Monheim. The problem area needed to be structured with an emphasis on social-spatial aspects, services and facilities, already existing resources, and networks. Evaluation reports on the single parts of the project are being issued on a continuous basis during the project time. Recommendations for action are being developed.

## Starting Point

One general impact of material poverty is the reduction in human and social resources. This means a loss of social participation as a consequence of a process of impoverishment. Accordingly, any definition of poverty prevention will have to focus mainly on the perception of the resources still available in order to strengthen or expand them. Poverty prevention means assuring social participation for those threatened by poverty. Additionally, they should be able to earn an income that assures their existence and receive assistance in active self- help. Another issue of poverty prevention is the importance of stabilising self-confidence in the context of daily life. To look at poverty from the perspective of children opens up a broader understanding of the term poverty and leads to

the necessity to rethink and further develop already existing concepts of prevention and coping with poverty. Child poverty always starts within the family’s poverty. Children’s poverty can be explained as inadequate provision followed by development deficits.

The consequences of family poverty can be already observed during a child’s preschool years. It can be shown that poor children are deprived twice as much as non-poor children with regards to their financial, social, cultural and health situation. Increasing numbers of young children in Germany are living in or threatened by poverty. The group of children at pre-school and elementary school age have a higher rate of poverty than the total group of children under fourteen years old. Services responsible for socialisation and social support/help programmes are therefore particularly needed[1]. These are today the most prominent places where poor children appear in public and where children and their families can/should receive adequate support and help. However, these facilities are rarely prepared.

Poverty prevention starts in day-care centres and focuses on the conditions and problems of socialisation at the local level. Poverty prevention is only possible or certain here through the work of professional staff in the facilities and projects. In addition, the engagement of individuals from the children’s social networks plays an important role. Preventive programmes for children have to create and form existential chances for the children’s development and support and strengthen their environment, in particular the family.

## Theory and Conception

Whether and why any measure can contribute to the solution of a specific problem area is linked to the evaluation of that measure. The evaluation itself is expected to give a sufficient answer to these questions by means of observation and presentation of the model’s progress, the assessment of its use, the effects and side-effects, and possible carryover. Our evaluation approach is based on the concept of experimental evaluation. It is therefore participative and responsive and accentuates the strong ties between practice development and research. In this context, cooperation between research and practice is crucial both in

developing research questions and methods as well as interpreting and transmitting results.

The objective is to support the model project - seen as a *learning project* - through conceptual ideas and regular data feedback and not just provide a final project assessment at the end. This means a strong cooperation of all project's participants, in particular with the coordinator from Mo.Ki. The scientific support of the ISS is composed of three main tasks:

1. Support the development of the concept
2. Professional support of testing and implementation
3. Analysis and documentation

## Method

The project is being conducted in the *Berliner Viertel*, a district in Monheim in particular need of renewal. The project starting-point are the day-care centres and all existing centres are cooperating. A centrally located day-care centre is the coordination point for the child and youth support of Monheim and during the project's running time operated by local government staff. This guarantees the necessary contact between the children, their parents and trained staff. A programme of prevention aiming to avoid the consequences of poverty has to be based upon an extensive working approach and includes the following areas:

- Creating and securing the foundation of the day-care centres (i.e. by staff qualifications, developing teaching ideas, networking and Marte Meo[2])
- Wider range of projects for parents and children (i.e. open lunch, parent's café, cultural projects in the district)
- Quick and unbureaucratic help for children and parents in the district (i.e. around-the-clock emergency service, hotline)
- Creating a broad support base for children and their parents by connecting to existing projects in the community (i.e. individual carers and care in social training groups)
- Strengthening and supporting parent education (i.e. by connecting the programmes offered during pregnancy, birth and parenthood)
- Concrete support for families through cooperation of local services and counselling offices

- Information material in doctors’ surgeries, shops etc.
- Family education programmes (i.e. FuN$^3$)
- Further training of pre-school teachers, teachers, doctors and parents about the causes and perception of behavioural problems and neglect
- Integration of voluntary engagement to support and apply family skills in day-care facilities (i.e. cooperation with sport clubs, music schools, adult education centres and libraries)
- Development of a cooperation network including the existing services and counselling offices in Monheim

## Objectives

The project aims to initiate a concept for local government in order to avoid the negative effects of family poverty on the situation and development of children. The idea is to grant support and counselling for parents and children in a district with an identified need for renewal. Often in these areas economic deprivation and social disadvantages are intertwined. In order to avoid child poverty in the long run the work done in day care centres should be developed into a nodal point for local government youth assistance. Programmes should be integrated into the day-care centres for helping children and families directly and simplifying their dealings with local government agencies.

## Research Questions

A major point of scientific evaluation is analysing the effectiveness of the measures undertaken. The following questions are of interest for the investigation:

- Which concepts and activities with the goal of poverty prevention have been developed and applied?
- Have the identified target groups in the *Berliner Viertel* been reached?
- Have the measures for poverty prevention been accepted in the district?
- Which measures in the model project proved particularly successful? In which way were these offers structured?
- Which framework helped the successful implementation of the measures in a special way?

- Which qualifications are necessary for staff for successful implementation?
- How were the measures connected to other programmes or social services in the *Berliner Viertel*?
- Are there any pointers for the integration of the measures into poverty prevention strategies at local government level?

## Interim Results

The analysis of the problems in the *Berliner Viertel* leads to three fields of action:

1. Expansion of preventive programmes for children that meet the demand for quality day-care facilities.
2. Measures for parent counselling and education in order to strengthen the resources of families.
3. Coordination and connection of existing programmes as well as provision of support and ideas for new initiatives in the *Berliner Viertel.*

Day-care facilities are an important starting point for accessible programmes because most families use them. The coordination of programmes by Mo.Ki enables a faster flow of information and reduces administrative tasks. The remaining central areas of work are:

### Preventive Programmes for Children: Care and Early Support

To take early promotion of children seriously means to promote the qualitative and quantitative expansion of day-care outside of the family in order to prevent social exclusion. In particular, it is necessary to increase capacity for children 0-12 years old in terms of more flexible opening hours, and more staff in those facilities with a high percentage of poor and socially excluded children. Correspondingly, structures ought to be developed that enable different support programmes in day-care centres.

### Strengthening Parent Skills

The ISS study on poverty in early childhood could reveal that the following factors have a positive effect on a child’s well-being:

- Regular activities within the family
- Good atmosphere in the family
- At least one parent with a good knowledge of German
- No family debts
- Adequate living conditions

The last factor is being promoted at the moment in the *Berliner Viertel* by enlarging apartments. Additional help is provided by the debt counselling service. The remaining points are undoubtably covered by the parent and family education programmes.

### Network of Cooperation ‘Monheim for Children’

Monheim has developed – within the housing policy framework for the *Berliner Viertel* - an extensive programme of measures in order to improve the image of the *Berliner Viertel* as a place for living. It aims to increase the satisfaction of living in the neighbourhood and create a more positive atmosphere there. With this in mind, it is necessary to continue the joint cooperation between day-care facilities and schools and connect with other social services in Monheim. The Mo.Ki model project is able to successfully build on the precious work of local government and close an important gap by building up a network of cooperation for children.

### Notes

1 These services are regulated by the German children and youth assistance act (Kinder- und Jugendhilfegesetz, KJHG)

2 *Marte Meo* is a project that has been developed first for the Netherlands. The target group of *Marte Meo* are pre-school teachers. By means of videos, practical knowledge can be gained about which supportive behaviour is necessary in order to support the development of children and how an educational situation can be used for child development. Accordingly, video material helps to understand how an individual child takes initiatives and how this child can be supported in its development taking into consideration the social, emotional, verbal and intellectual development of the child.

3 FuN developed out of the American programme FAST (Families and Schools Together) and stands for Family and Neighbourhood. The programme runs for eight weeks and is designed for socially disadvantaged families and is held in an educational facility in their neighbourhood.

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## Summary of Workshop Results

# Social and Emotional Factors

Based on the following central questions:

1. What consequences does poverty have for the social and emotional development of children?
2. How many children in Germany are affected?
3. What does a successful project/programme that minimises the negative influences on the social and emotional development of children look like?
4. Which responsibilities should be assumed and by whom? State, non-state institutions, parents – who should become active and when?
5. Where do we stand with our own work?
6. Is the project presented transferable to countries in the global South?

Participants discussed the project presented from the town of Monheim on planning preventative help for children and young people.

The following possible effects on social and emotional development were identified as consequences of poverty:

- emotional regression, developmental delay.
- insufficient care (material, health, cultural) => feelings of inequality, health problems, etc.
- inappropriate development, too much responsibility for children (especially when children have to stand in for working parents and take on adult responsibilities)
- discrimination, prejudices, isolation; non-development of social skills
- non-recognition of performance due to poverty

In Germany every sixth child is affected by poverty. Identified as being in special danger are families in which one/both parent(s) are psychologically sick, single parents and families with a background of immigration.

Components of a successful programme must involve support where possible right from the time of conception, at the latest in early childhood, a solid financial basis and a comprehensive networking of services (holistic approach). Necessary is the will and the readiness for change, even at the political level.

It is important in assigning areas of responsibility to consider having a *single* contact point for guidance and (interface) coordination, preferably based in the local authority. This also sets targets. Further areas of responsibility are for example, drawing up guidelines and developing quality standards.

All stakeholders (especially coordinating centre, children and parents should be involved in gathering data, project planning and realisation. This relates also to networking as well as gathering information on services (e.g. in kindergarten groups by parents). Everyone can also be involved in resource acquisition.

Important partners in the areas of promotion and on-going support could be social and non-governmental organisations (e.g. for supporting a test phase)

Gaps in implementation in Germany or potential and possibilities for improvement were seen in various areas:

- implementation of legal right for 0-3 year olds to a pre-school place
- drawing up a draft law on help in early childhood
- access to education for everyone
- knowledge about the connection between poverty and disability
- intensification of preventative measures
- acceptance of the UN Convention on the Rights of Persons with Disabilities
- raising awareness in (state) system
- reviewing budget items and distribution
- improvement of data protection

The participants were unanimous that the project presented can indeed be transferred in an adapted form to countries of the global South. Important in doing so is that assistance be child-based, taking the needs of the children as its starting-point (cross-provider approach). Resources and support programmes are available in many countries and can be made known and networked with one another, just as non-governmental organisations have to be networked with government, state institutions and economic partners and skills be used in concert. Special significance was given to a south-south exchange of experience and training.

*Friederike Kugler*
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Workshop Facilitator

# Part II: Inclusion of Children with Disabilities in Early Childhood Programmes

# “Nothing about us without us”. The Paradigm Shift from a Welfare Approach to a Rights-Based Approach

*Guido Falkenberg*
Kindernothilfe

Before dealing with early childhood development again and in more detail, I was asked to describe the shift from a welfare model to a human rights-based model, which in a sense is the whole point of our two-day considerations. As an example of this, I will take a reflective look at the practical experience of my own organization, the Kindernothilfe (KNH).

Kindernothilfe was founded in 1959 as a Christian, evangelical mission organization, pursuing the motive of Christian charity. In the beginning, the aim was to provide individual famine relief for children in India. From today’s point of view, we would call the method applied a somewhat paternalistic *welfare approach*, acting on the assumption of passive welfare recipients. The gratitude of the recipients of this beneficence was an intrinsic aspect of this approach. At the end of the 1950s, however, this was a largely unquestioned concept for providing help.

In the first ten years of existence, Kindernothilfe focussed on sponsoring children in pupil’s homes. At the beginning of the 1960s, the program was expanded for the first time. Day-care centres and special facilities for children with disabilities were included. In the 1970s, more and more homes for children suffering from polio, facilities for children with hearing and seeing impairment, for mentally disabled children and children with cerebral palsy were built increasingly. The primary goal was the medical rehabilitation in special facilities. This system of service delivery approach for individuals was not fundamentally questioned until the end of the 1970s.

From the 1980s onwards, however, controversial debates in the development policy community as to whether this welfare-based project approach was still sufficient, increased.

Was this concept of medical rehabilitation in special facilities stable and sustainable? These questions were raised ever more insistently. Not only in KNH,

but in the entire development policy debate, terms like *community development* or *empowerment*, rights-based approach, self-help concept and participation of target groups were introduced.

At the beginning of the new century, the Millennium Goals were adopted, which meant the increased consideration of poverty reduction strategies in regard to development cooperation. In this context, the term *relevance* was introduced. What relevance does development cooperation have with respect to the poverty in a country? The two major UN Conventions of the 21st century, namely on the rights of persons with disabilities in 2006 and on children's rights, certainly promoted the paradigm shift as well.

All these fundamental, conceptual debates, which lasted 20 years, as well as the UN Conventions have had their effects on the projects and programmes of KNH. Today, KNH's work is not based on welfare or care anymore, but on human, especially children's rights. Therefore, today, we regard ourselves as a children's rights organization.

## Consequences for Development Cooperation

Such a paradigm shift from a welfare approach to a rights-based approach is a powder keg in itself. In my opinion, the primary problem is not even justifying the paradigm shift, or making it comprehensible. The UN Conventions and the corresponding policy papers alone show clearly that the framework for development cooperation, both at state and civil society level, is the human rights-based approach.

Today, everybody employed in development cooperation knows in principle that people in partner countries with whom we work together in development cooperation have legal capacities, that they are not more or less passive objects of our care, but that target groups need to be engaged to participate actively in the projects and programmes from the start, and that especially children, adolescents and persons with disabilities need to be involved equally in the jointly initiated development process.

This means amongst other things that, wherever possible, we look for Disabled People's Organizations (DPOs) in the project areas and, where the needs

of disabled persons are affected, actively involve them in project planning and implementation.

Basically, these are well-known facts. In my opinion, the challenge is firstly, the implementation of this knowledge into practical work and secondly, that this paradigm shift needs to be discussed and accepted beyond employees in development cooperation by the respective civil societies. In other words, the paradigm shift needs to be implemented structurally in the respective development cooperation organizations, and needs to be included in practical politics and civil society discussions.

Regarding the paradigm shift, the new view of the world so to speak, the UN Conventions on the Rights of the Child and on the Rights of Persons with Disabilities are essential preconditions. This is even more acute for governmental development cooperation than for NGOs, as after signing the UN Conventions, Germany is obligated by international law to put them into political practice, for example by the BMZ (German Federal Ministry for Economic Cooperation and Development) and the GIZ (German Society for International Cooperation). And political practice implies changing funding guidelines if necessary.

But what can NGOs do to embrace the human rights approach in their work? What can be done in practice? Taking the Kindernothilfe as an example, as I said, implementation is the first great challenge. KNH took first conceptional and structural steps to implement the human rights-based approach more and more in its projects. So for example, the management installed working groups to introduce the children’s rights-based approach. Among them is a group working on disability mainstreaming. With the VENRO Handbook, an *inclusive development* concept was described, making sure that persons with disabilities in the large child-centred community based projects (a cluster of 15 to 20 villages and several thousand families) are actively involved and encouraged as groups and as individuals from the start (This is from the start in the participatory poverty analysis, and later on with regard to education, health, income generating activities, infrastructure, advocacy…).

Furthermore, persons with disabilities become more and more involved in KNH’s self help approach. This approach has become a decisive means for sustainable poverty alleviation. The poorest of the poor, mainly women, are

empowered socially, economically and politically to lead a life in dignity in the midst of society with their families and children. Although every fifth person amongst the poorest of the poor has a disability, in the framework of this approach, they have not played a role as a group so far.

In the future, we will check whether our partners are actually working on the basis of human and children's rights or not. This will be an essential criterion for deciding on cooperation with other organizations in the future.

However, for me personally, the decisive question is whether it works in establishing the *rights of marginalized groups* among civil societies and their actors in Germany and partner countries in the South, with their different cultural contexts. There is still a lot of work to be done.

# Identification of Child Disabilities in Low- and Middle-Income Countries

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Many low- and middle-income (LAMI) countries have seen steady improvements in child survival in recent decades due to expanded immunization, oral rehydration and other public health interventions. Coinciding with this trend is a growing global awareness of child development and concern with not only survival but also the functioning and quality of life of children who survive. However, little is known about the frequency of child disability in many LAMI countries and the situation of children with disabilities. Furthermore, there is no established best method for identifying children with disabilities in LAMI countries. Improvements in survival may be accompanied by increases in the prevalence of child disability, thus it is vital that progress be made to improve the detection of child disability, prevent future cases, and ensure the equal rights and participation of children with disabilities in LAMI countries, where an estimated 80% of the world's children live.

Obtaining a sound estimate of child disability in LAMI countries has the potential to raise awareness about disabilities and reduce stigma and discrimination. Better information about child disability would enable the identification of risk factors to inform strategies to prevent disability. An improved understanding of the magnitude of the issue of child disability may also encourage the development of services (both preventive and support/rehabilitation) for children with disabilities and their families, and make monitoring and improving the quality of life of participants more feasible.

Disability is defined herein as consistent with the United Nations Convention on the Rights of Persons with Disabilities and the International Classification of Functioning, Disability, and Health. Within this framework, disability can be experienced in one or more of the following three dimensions: *Impairments*, defined as significant deviations or loss in body function or structure; *Activity Limitations* or difficulties in executing activities; *Participation Restric-*

*tions*, defined as limited involvement in social, work, or other events and activities.

In countries that have well-established early childhood education programs, medical facilities, and services for children at risk for disability, administrative data and registries are useful means of identifying child disability in the population. However, in many LAMI countries, and particularly in communities where children live in poverty, such programs and data are not available. Thus other methods must be employed in order to obtain information about children with disabilities. Birth cohort studies follow a group of people born at a particular time and can be used to track disability prevalence, however these studies are uncommon in LAMI countries. Key informant surveys, which rely on reports from key members of a given social group about the disability status of residents, are another technique that has been proposed. However, previous studies suggest that key informant reports systematically miss children with less obvious, non-physical disabilities (e.g. children who have cognitive disabilities, those who may have hearing or vision impairments).

An alternative strategy is the Ten Questions (TQ) screen and two-phase design for monitoring child disability in LAMI countries. In phase 1, the TQ screen is given to all children in a population. Children who screen positive to the TQ are considered to be at high risk of disability. In the second phase, children who screen positive to the TQ are referred for clinical/diagnostic assessments to evaluate and confirm disability status. It is recommended that a sample of children who screen negative to the TQ also undergo clinical assessment to: 1) enable evaluation of the validity of the TQ as a screen in the given population, and 2) identify children with disabilities who screened negative to the TQ (these are likely children with mild disabilities or transient functional limitations).

The TQ screen asks the primary caregivers of children 2-9 years old ten simple yes/no questions. Children are identified as having screened positive to the TQ (or to be at increased risk of disability) if their parent or guardian suggested a problem in response to one or more of the ten questions. The TQ is designed to be applicable in almost any cultural setting by asking about a child's universal functional abilities relative to their peers, and takes into account parents' or

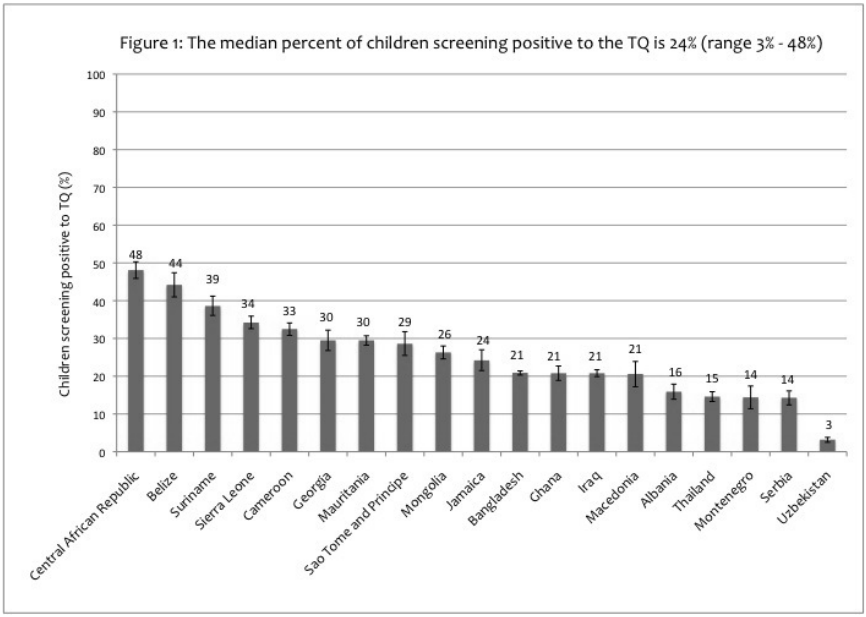
guardians' perceptions given their particular cultural context. The TQ is a relatively low cost screen that is easy to administer, and has been the most commonly used tool in LAMI countries. Moreover, several international studies support the validity and reliability of the TQ. The utility of the TQ screen alone (without follow-up clinical or diagnostic assessment) is to identify children who are in need of referral for additional evaluation and possibly for rehabilitation services. It is not intended to be a stand-alone tool to estimate prevalence of child disability or any particular type of disability in a population.

Though the TQ has been shown through previous studies to be reliable, feasible, and valid across cultures for detecting serious cognitive, motor and seizure disabilities in 2-9 year old children, it is not without limitations. Previous studies suggest that the TQ has a low sensitivity for identifying previously undetected vision and hearing disabilities as well as mild impairments. The TQ is not designed to detect behavioral disabilities including autism. However, current work is underway in India and Uganda to expand the TQ for behavioral screening. The TQ is not diagnostic – we cannot infer a child has a disability based on screening status alone, nor what type of disability a child may have based upon screening status.

Despite the limitations of the TQ, it is considered the most effective screen for obtaining estimates of children at increased risk for disability. UNICEF recommended the inclusion of the TQ in the third round of its Multiple Indicator Cluster Survey (MICS3). The MICS3 household survey was administered in 53 countries during 2005-2006, and collected cross-sectional data about several indicators of women and children's health. Nineteen of the 53 countries participating in MICS3 used the TQ to evaluate child disability. Though UNICEF recommended that countries using the TQ follow-up screening with the second-phase clinical assessments, these were not carried out due to resource limitations.

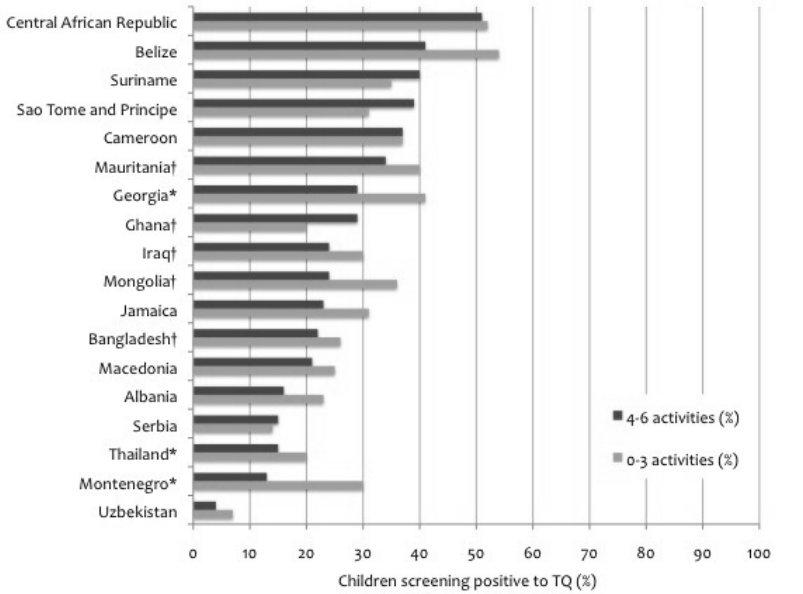
We analyzed the cross-sectional child disability screening data collected during MICS3 and examined associations between nutritional variables, early learning activities, school participation, and risk for disability. Over 200,000 children were screened, suggesting it is feasible to carry out this type of screening in resource-limited countries. A median 24% of children screened positive

for disability in the 19 participating countries, ranging from 3% in Uzbekistan to 48% in Central African Republic.




Among younger children (ages 2-4 years), those who participated in fewer early-learning activities screened positive to the TQ (for increased risk of disability) significantly more frequently than children who participated in more activities in eight of the 18 countries for which these data were collected. Early learning activities questions asked whether in the past three days a parent had partaken in any of the following activities with the child: reading books, telling stories, singing songs, taking outside, playing, counting/naming objects.

Figure 2: Children 2-4 years of age who participated in more early learning activities screened positive to the TQ significantly less frequently than children who participated in fewer early learning activities in 8 if 18 countries.




Rao-Scott $\chi 2$ p-values: * $p < 0.05$, ‡ $p < 0.01$, † $p < 0.001$

Screening positive to the TQ was significantly more likely among children who were not breastfed compared with children who were in eight of 18 countries. Children who never received vitamin A supplementation screened positive to the TQ more frequently than children who have in five of ten countries. Children meeting World Health Organization criteria for stunting and underweight were significantly more likely to screen positive than other children (in seven of 15 and eight of 15 countries, respectively).

Children 6-9 years of age who did not attend school were more likely to screen positive for increased risk of disability than children who attended school in eight of 18 countries. These results could reflect the fact that children who do

not attend school are less likely to develop typically or that children with disabilities are kept home from school (because of social stigma, because there is no appropriate teaching environment for children with special needs, etc.), or a combination of these relationships.

Children ages 2-9 years residing in the poorest 60% of households screened positive to the TQ more frequently than children residing in the wealthier 40% of households in six of 17 countries. These results highlight the variation in living conditions and wealth within LAMI countries, and that certain subpopulations within LAMI countries may be at increased risk for disability. This may reflect the fact that the poorest within LAMI countries often have greater exposure to risk factors (e.g. environmental, educational, and/or nutritional factors) contributing to poor development and the experience of disability.

The results of our analyses support a strong relationship between early childhood stimulation or education, nutritional status, and risk for disability. Children who participated in more early learning activities and thus had more stimulation screened positive to the TQ less frequently than children who participating in fewer activities. Children with better nutritional status screened positive to the TQ less frequently than children with worse nutritional status. Children attending school screened positive to TQ less frequently than children not in school. These results may reflect the fact that stimulation is related to development and/or that there is widespread discrimination against children not seen to be developing typically. Similarly, our results could indicate that nutritional deficiencies are a risk factor for some disabilities and/or that children with disabilities have reduced growth potential or access to food. Unfortunately, we cannot infer any directionality or causality from the correlations based on the cross-sectional data collected in MICS3.

Cross-country comparisons must be made cautiously as there may have been some variation in survey administration across participating countries. Cultural biases about disability or particular questions of the TQ, issues with translation of the TQ screen, inconsistencies in sample selection, or differences in who responded to the TQ may have influenced results. Additionally, data management techniques (such as quality assurance, data cleaning, dealing with missing data) may have varied between participating countries.

Since the TQ is not designed to specifically address issues of stigma, inclusion, or discrimination, we could not evaluate these issues using these data. Furthermore, without follow-up clinical assessments, evaluations of the validity of the TQ in participating countries could not be conducted. We caution against generalizing findings from this study to all LAMI countries, as the variation observed between and within participating countries likely applies to other countries not included in this study.

Despite these limitations, these and other multinational findings provide evidence of the substantial global impact of child disability and the fundamental association of poverty with child disability. Poverty and disability are linked via nutrition (access to healthy food, clean water, micronutrient and protein-calorie deficiencies) and education (early learning activities, schooling), among other factors. Discrimination against those with disabilities may lead to fewer educational and employment opportunities that may in turn result in poverty. Achieving Millennium Development Goal One, to reduce poverty and hunger, will require targeting those at highest risk of the negative impacts of poverty, including children at risk for disability or poor developmental outcomes.

These results draw attention to the need for improved global capacity to assess and provide services for children with disabilities and their families. Such services include both assessment for early detection and evaluation of child disability and interventions that ensure equal participation of children with disabilities in all aspects of society, perhaps via community-based rehabilitation. Addressing factors related to living in poverty such as nutritional deficiencies, access to stimulation/early learning activities, and education may also improve outcomes for children at risk for disability.

## Conclusions

These results provide internationally comparable data about the frequency and status of children with disabilities in several LAMI countries. There are important associations between nutritional status, early childhood exposure to stimulating activities, education, and risk for disability. Further research is needed in LAMI countries to understand the role of poverty, nutritional deficiencies, and restricted access to learning opportunities as both potential antecedents of child-

hood disability and consequences of discrimination. Early identification of children at risk for disabilities may improve child development outcomes by offering such children access to targeted services.

## Implications and Strategy

Ultimately, the administration of surveys and dissemination of results is not sufficient. Improvements must be made in our ability to monitor child disability and development in LAMI countries to ensure the full, equal participation of children (and adults) with disabilities. This will require the development of public health, primary health care, and educational infrastructure to:

1) improve monitoring and assessment of child disability, including clinical assessment to confirm screening results;
2) increase capacity for support service provision to children with disabilities and their families;
3) enhance and expand programs promoting equal rights and opportunities of children with disabilities.

Greater international attention to these issues has the potential to mobilize resources to achieve these goals.

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# Community-Based Rehabilitation (CBR) - a Common Strategy in the Developing World for Rehabilitation, Poverty Reduction and Promotion of Human Development

*Compiled by Gabriele Weigt from the presentation made by Chapal Khasnabis,*
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## Background

Following the Alma-Ata declaration[1], the World Health organization (WHO) introduced community-based rehabilitation (CBR). In the beginning, CBR was primarily a service delivery method making optimum use of Primary Health Care (PHC) facilities and community resources. The main aim was to bring rehabilitation services closer to people with disabilities, especially in low-income countries. In the early years, CBR programmes focused on physiotherapy, assistive devices, and medical or surgical interventions and were more dominated by rehabilitation personnel. Some programmes also introduced education activities and some very low-level skills training or income-generating programmes, which ultimately failed to produce the desired result. People with disabilities were often perceived as *poor patients* whose problems needed to be corrected – this type of approach was labelled the *medical model.*

A focus group discussion in India revealed that what professionals think are the needs of the people with disabilities are quite opposite to what people with disabilities and their

| Common perception (Medical model) | People's need (Developmental context) |
|---|---|
| Physiotherapy | Income |
| Assistive devices | Food |
| Corrective surgery | Clothes |
| Education/schooling | House |
| Accessible classroom & toilet | Water & toilet |
| Accessible environment | Education – School |
| Vocational training | Treatment or Cure |
| Income | Calipers/Shoes/exercise |

Box 1: Outcome of Focussed Group Discussion

families, especially those who are poor, consider as priorities (box 1). Quite often people's basic needs have been ignored; poverty and human development issues were completely overlooked by the traditional CBR implementers.

However, during the 1990s, along with the growth in the number of CBR programmes, there were changes in the way CBR was conceptualized. Involvement of other UN- agencies such as the International Labour Organization (ILO), United Nations Educational, Scientific and Cultural Organization (UNESCO), United Nations Development Programme (UNDP), and United Nations Children's Fund (UNICEF) made CBR multi-sectoral rather than focussing only on medical rehabilitation.

## Disability and Poverty

Though people with disabilities are disproportionately poor and often deprived of benefits from the development sectors, the Millennium Development Goals (MDG) have ignored disability. In any communities, the poorest of the poor are people with disabilities. Poverty is both a cause and consequence of disability[2]: poor people are more likely to become disabled, and disabled people are more likely to become poor. While not all people with disabilities are poor, in low-income countries people with disabilities are over-represented among the poorest. Often they are neglected, discriminated against, and excluded from mainstream development initiatives, and find it difficult to access healthcare, education, housing and livelihood opportunities. This results in greater poverty or chronic poverty, isolation, and even premature death. The costs of medical treatment, rehabilitation services and transport also contribute to the poverty cycle of many people with disabilities. Addressing disability is a concrete step to reducing the risk of poverty in any country. At the same time addressing poverty can reduce disability. So poverty needs to be eliminated in order to achieve a better quality of life for people with disabilities and their families.

Over the years, CBR practitioners also started realizing that unless and until poverty and basic needs are addressed, CBR cannot be effective, so CBR needs to equally focus on rehabilitation, poverty reduction and human development. This realization was quite apparent during the international consultation to review community-based rehabilitation, which was held in Helsinki in May 2003[3].

It was recommended that CBR programmes needed to embrace a multisectoral approach to reduce poverty. Ensuring access to healthcare, education, livelihood opportunities and social benefits are definite steps to reduce poverty among people with disabilities and their families.

> "Unless disabled people are brought into the development mainstream, it will be impossible to cut poverty in half by 2015 or to give every girl and boy the chance to achieve a primary education by the same date – [which is among] the goals agreed to by more than 180 world leaders at the UN Millennium Summit in September 2000". James Wolfensohn, former President of the World Bank (*Washington Post*, December 3, 2002)

In 2004, the ILO, UNESCO and WHO updated the first CBR Joint Position Paper to accommodate the Helsinki recommendations. The updated Joint Position Paper[4] reflects the evolution of the CBR approach from service delivery to community development. It redefines CBR as **"**a strategy within general community development for the rehabilitation, poverty reduction, equalization of opportunities and social inclusion of all people with disabilities and promotes the implementation of CBR programmes "…through the combined efforts of people with disabilities themselves, their families, organizations and communities, and the relevant governmental and non-governmental health, education, vocational, social and other services".

## Convention on the Rights of Persons with Disabilities and CBR

On 13th December 2006, the UN General Assembly adopted the *Convention on the Rights of Persons with Disabilities*[5] and it came into force on 3 May 2008. The main purpose of the convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. The Convention needs practical strategy or tools for its implementation. During the development of the convention, WHO in partnership with ILO, UNESCO and International Disability and Development Consortium (IDDC) started developing the *CBR Guidelines.*

CBR is a multisectoral, bottom-up strategy, which can ensure the Convention makes a difference at the community level. While the Convention provides the philosophy and policy, CBR is a practical strategy for implementation. CBR activities are designed to meet the basic needs of people with disabilities, reduce poverty, and enable access to health, education, livelihood and social opportunities – these activities all fulfil the aims of the Convention. As CBR is a strategy implemented mostly in developing countries it is essential to address issues related to the poverty, empowerment and sustainability.

## CBR Matrix

The evolution of CBR into a broader multisectoral community-based development strategy has resulted in the emergence of a matrix to provide a common framework for CBR programmes (fig. 1). The CBR matrix consists of five key *components* – the health, education, livelihood, social and empowerment components. Within each component, there are five *elements*. The first four components relate to key development sectors, reflecting the multisectoral focus of CBR. Good coordination among these four sectors is essential to enhance the quality of life of people with disabilities. The final component relates to the empowerment of people with disabilities and their families, which is fundamental for ensuring access to the services of the key development sectors, achieving human development and enjoying human rights. It is not expected that one CBR programme will have the capacity to cover all the five components and their elements. However, programmes will need to collaborate with others – focusing only on health or education or livelihood will have limited benefits for people with disabilities and their families. The CBR matrix provides the necessary framework for the *CBR Guidelines* and the new direction for making development inclusive and community-based.

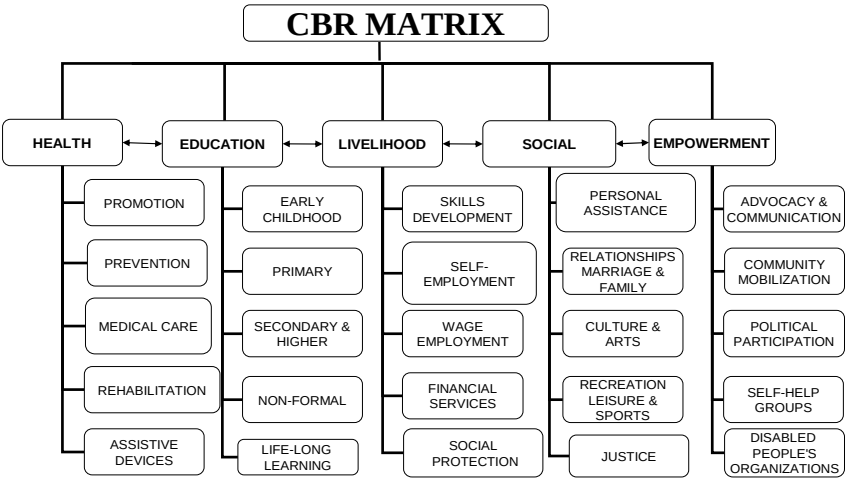


Fig. 1: CBR matrix

## Disability Inclusive Development

Inclusive development is that which includes and involves everyone, especially those who are marginalized and often discriminated against[6]. People with disabilities and their family members, particularly those living in rural or remote communities or urban slums, often do not benefit from development initiatives and therefore disability inclusive development is essential to ensure they can participate meaningfully in development processes and policies[7]. Mainstreaming (or including) the rights of people with disabilities in the development agenda is a way to achieve equality for people with disabilities[8]. To enable people with disabilities to contribute, to create opportunities, share the benefits of development, and participate in decision-making, all development initiatives need to adopt an inclusive approach. It is a human rights issue and countries ratifying the convention are now legally bound to ensure people with disabilities are part of all development sector initiatives. The *CBR Guidelines* provide the necessary direction to make the four key development sectors inclusive of people with disabilities.

## Community-Based Approaches to Development

Development initiatives are often top-down, initiated by policy-makers at locations far removed from the community level, and designed without the involvement of community members. It is now recognized that one of the essential elements of development is involvement of the community as individuals, groups or organizations, or by representation, in all stages of the development process including planning, implementation and monitoring[9.] A community-based approach helps to ensure that development reaches the poor and marginalized, and facilitates more inclusive, realistic, and sustainable initiatives. Realizing this, many agencies and organizations promote community-based approaches to development, e.g., Community Driven Development (CDD)[10] initiatives by the World Bank, and Community-Based Initiatives (CBI)[11] by the World Health Organization. The *CBR Guidelines* take the best examples of these approaches and provide a roadmap to make the key development sectors inclusive of people with disabilities with a community-based approach; so the benefit of development reaches more people with disabilities especially those who live outside of big cities. Experience shows that these types of approaches make CBR and other development initiatives more realistic and sustainable.

As community involvement is an essential element of development, the *CBR Guidelines* strongly emphasize the need for CBR programmes to work with community members, and local governments in particular. It highlights the need for involvement of the community to address disability, poverty, and development issues. Empowerment and community involvement (including local government) are at the core of any CBR programme. The *CBR Guidelines* also embraces the human development approach; especially through its empowerment chapter, which campaigns for creating an environment in which people with disabilities, like others, can develop their full potential, make their own decisions, and lead productive and creative lives in accordance with their needs and interests.

## Overall Objectives of the CBR Guidelines

Following the publication of *CBR Joint Position Paper*, CBR stakeholders worked collaboratively to produce the *CBR Guidelines*, which promote CBR as

a strategy which can contribute to implementation of the Convention, and of disability inclusive national legislation, and which can support community-based inclusive development. The guidelines provide CBR managers, among others, with practical suggestions on how to develop or strengthen CBR programmes and ensure that people with disabilities and their family members are able to access the benefits of the health, education, livelihood and social sectors. The guidelines have a strong focus on empowerment through facilitation of the inclusion and participation of disabled people, their family members, and communities in all development and decision-making processes. The *CBR Guidelines* adopt a twin-track approach, which ensures that 1) disability issues are actively considered in mainstream development work, and 2) more focused or targeted activities for people with disabilities are provided where necessary. The suggested activities within the *CBR Guidelines* are based on the twin-track approach.

The Key Objectives of the *CBR Guidelines a*re:

- To provide guidance on how to develop and strengthen CBR programmes in line with the *CBR Joint Position Paper* and the *Convention on the Rights of Persons with Disabilities.*
- To promote CBR as a strategy for community-based inclusive development to assist in the mainstreaming of disability in development initiatives, and in particular, to reduce poverty.
- To support stakeholders to meet the basic needs and enhance the quality of life of people with disabilities and their families by facilitating access to the health, education, livelihood and social sectors.
- To encourage stakeholders to facilitate the empowerment of people with disabilities and their families by promoting their inclusion and participation in development and decision-making processes.

## Scope and Purpose of the *CBR Guidelines*

The focus of the Guidelines is to provide a basic overview of key concepts, identify goals and outcomes that CBR programmes should be working towards, and provide suggested activities to achieve these goals. The Guidelines are not intended to be prescriptive – they are not designed to answer specific questions

related to any particular impairment, provide recommendations for medical/technical interventions, or provide a step-by-step guide to programme development and implementation.

The *CBR Guidelines a*re presented in seven separate booklets:

- Booklet 1 – the Introduction: provides an overview of disability, the *Convention on the Rights of Persons with Disabilities*, the development of CBR, and the CBR matrix. The Management chapter: provides an overview of the management cycle as it relates to the development and strengthening of CBR programmes.
- Booklets 2–6 – each booklet examines one of the five components (health, education, livelihood, social, and empowerment) of the CBR matrix.
- Booklet 7 – the Supplementary booklet: covers four specific issues, i.e. mental health, HIV/AIDS, leprosy and humanitarian crises, which have historically been overlooked by CBR programmes.

## Some Key Activities from the *CBR Guidelines*

Among all the suggested activities, some key activities mentioned in the *CBR Guidelines* are as follows:

- CBR personnel need to work with people with disabilities, their families, and community members as community development workers or change agents rather than rehabilitation workers.
- Ensure disabled people and their family members are included in all community development initiatives. If required, provide training and support to the implementers of those programmes so that they have the knowledge required to include people with disabilities.
- Create awareness in the community to overcome stigma and prejudice. Ensure disabled people are valued and treated as equal members in the community.
- Start early - ensure children with disabilities are identified and registered at birth; are included in regular screening and immunization programmes; and have an assessment of their short and long-term needs.

- Arrange or facilitate immediate health care/rehabilitation intervention to address avoidable impairments - delay in intervention can result in life-long dependency and even premature death. Early identification and early intervention is key, and the most cost effective.
- Ensure children with disabilities are included in nutrition, development and education programmes. Bringing the child out of their hut or house is often the first step towards childhood development and inclusion.
- Break down barriers - talk to school authorities to facilitate inclusive education, and if needed support the school authorities to make the schools inclusive.
- Visit people with disabilities rather than waiting for people to come to you. Many people with disabilities cannot travel far from their homes especially if they are poor and daily-wage earners.
- Include everyone – all impairment groups, irrespective of their causes of impairment and socioeconomic condition.
- Facilitate therapy services close to where children live e.g. at schools and community centres.
- Support barefoot professionals or find alternatives – family members and neighbours can be a good resource for carrying out simple exercises and to teach daily living skills. It is better to provide therapy through sports and child-centered play or recreation activities.
- Children's parliaments are a good initiative to create awareness, promote inclusion, childhood development & introduction of Rights-based Approach. Local problems often have local solutions. Children can register all their problems including the problems of disabled children, and make a petition to local authorities.
- Address the root problem of poverty. Facilitate skills training in areas which are needed in local or adjoining markets. Apprenticeship, job coaching or mentorship programmes could be a good transitory approach before placing people with disabilities in the job market.
- Work with local authorities and business communities to ensure inclusion of people with disabilities in the job market so that they can become productive members in the society.

- Ensure people with disabilities who are poor are included in the poverty reduction programmes or in any other programmes dedicated for the poor.
- Where employment is not possible due to severity of the impairments, ensure social/financial assistance or support.
- The empowerment of people with disabilities and their families is fundamental to any CBR programme. A community which is empowered helps to ensure programmes are realistic, powerful and sustainable. Organizing and uniting people with disabilities and their families through self-help groups (SHG), parents' organizations and disabled people's organisations (DPO) ensures successful CBR programmes.

### The story of Ramesh

Ramesh is a young local unemployed youth living in Anekal, 70 km away from Bengaluru, India. He cannot walk due to polio and has never been to school either. He was a burden to his family and often subjected to prejudice and discrimination. Ramesh joined the Anekal CBR programme and soon became an active member. Anekal is known for its agricultural products and coming from a farmer's family Ramesh had some knowledge of farming. He was able to take a loan of €400 from the CBR programme to grow vegetables - within six months he had made a 100% profit. As a result of this success, he decided to borrow more money to grow potatoes, beans, tomatoes, other vegetables and even flowers. Today, Ramesh is a successful farmer, is married, is able to take care of his family and is confident that his child will have a normal childhood unlike his. He has paid back most of his loan, has a tricycle to move around and is now a valued family and community member. Ramesh is an example of how CBR can facilitate rehabilitation, empowerment, inclusion, poverty reduction, and human development.

## Conclusion

The *CBR Guidelines* were published in response to the many requests from CBR stakeholders around the world for direction regarding how CBR pro-

grammes can move forward in line with the Convention and inclusive development. The Guidelines provide, after 30 years of practice, a common understanding and approach for CBR; they bring together all that is currently known about CBR from around the world, and provide a new framework for action as well as practical suggestions for implementation. The Guidelines are strongly influenced by the *Convention on the Rights of Persons with Disabilities* and its optional protocol, which were established during development of the guidelines. The *CBR Guidelines* offer much-needed practical tips on how to operationalize the Convention and make development inclusive of people with disabilities and their families. Although the *CBR Guidelines* have primarily focused on developing countries, with the appropriate modifications and alterations it can be applied anywhere in the world. Considering the current global financial crisis and changes in and around the disability sector, CBR is more needed now than ever.

## Notes

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# A Successful Model of Early Detection and Early Intervention as Part of a Comprehensive Early Childhood Programme

*Sandy Padayachee*
SCDIFA Cheshire Home, South Africa

## Disability in the South African Context

People with disabilities in South Africa, like all South Africans, are covered by the 1996 constitution, which outlaws any discrimination against any person on any grounds. The country also committed itself to including people with disabilities in all areas of public life, including education, when the government ratified the UN Convention on the Rights of Persons with Disabilities in 2007.

The right of children with disabilities to education is also covered by legislation and government policy:

- The South Africa School Act (Act 84 of 1996) says that public schools must admit learners and serve their educational needs without unfairly discriminating in any way
- August 1999: Consultative paper on special education No. 1 Building an inclusive education and training system
- Education White Paper 6 – 2001 – gazetted in terms of the National Education Policy Act (ACT 27 OF 1996) provides education and the framework for an Inclusive Training System
- National Curriculum Statement 6th October 2003

Yet it is not possible to understand the situation for black South Africans with disabilities without considering the worlds of difference between people living in urban and rural communities, those with and without access to education, those with and without decent housing, and those with and without recognition or respect for their dignity and humanity.

Race is also still a big issue and an influence on social status in South Africa. Children with disabilities commonly experience difficulties resulting from social exclusion and marginalisation in association with their impairments, and this is compounded by issues of race. It is not possible to understand the situa-

tion of disabled children in South Africa without placing it in the context of the country's history.

## Programme Rationale

For every human being, the formative years from birth to age nine are considered to be the most crucial phase of development. The wellbeing of children depends on the ability of families to function effectively. Children need to grow up in a nurturing and secure environment that can support their development, protection, survival and participation in family and social life. These imperatives work together to lay the foundation for life. It is also important that the capacity of parents be strengthened and supported, to give their children the best possible start in life.

We therefore believe that all children should be provided with programmes that are relevant, appropriate and suitable to their capacity and circumstances, and that such intervention should be started as early as possible.

## SCDIFA Residential Home: our Programme Base

Our services to children with disabilities in Durban began in 1983 with the founding of SCDIFA residential home. The home is part of Cheshire South Africa, a national organisation that supports disabled people through facilities and projects across the country. Cheshire South Africa is, in turn, a member of the Leonard Cheshire Disability Global Alliance, a federation of disability and development organisations in 54 countries that shares good practice, supports the development of quality programmes and helps members campaign on disability issues.

SCDIFA provides care and rehabilitation for children with profound disabilities. It presently accommodates 39 children who according to our license from the Department of Health are termed *ineducable* and *non-trainable*. Over the years the children in our care began to show progress in language development, independence, memory, concentration and more socially acceptable behaviour.

As a result of these positive changes, the Board of Management decided to diversify our programmes to meet the needs of the children in the home and others in the community to ensure their continued progress.

Keeping in mind that none of our programmes is a *stand alone service* – each works in synergy with the others to complement each other and provide support so they are sustainable – our *richest resource* is our staff.

Fig. 1: Staff at SCDIFA

## Educare Day Clinic

SCDIFA runs the Educare day clinic at our home to support children through focusing on a developmentally appropriate curriculum. Emphasis is placed on what the child can do and what he/she can learn. Time or schedules imposed from the outside do not control the learning process and the children are able to develop at their own pace. The learning areas are arranged in such a way that the children can move around freely and have a choice of activities. These choices help children make decisions, explore and learn through play in a structured way.

Our vision for the day clinic is:

- To advance the best interests of the child in all matters affecting them
- To promote and enable the realisation of the child's right to survival, development, protection and participation
- To mobilise partnerships and resources at all levels

Fig. 2: Children and staff at the Educare day clinic

## Early Identification and Intervention

Since it is well established scientifically that the early years are critical in the formation of intelligence, personality and social behaviour, and that the effects of early neglect can be cumulative, we focus on early identification of children with disabilities. When issues are not identified, children's needs can compound over time and manifest themselves in behavioural difficulties, low self esteem, problems at school and worsening of impairments. Therefore we believe that early identification and intervention is particularly important when a child is young and when most potential damage can be avoided.

We started the Prevention, Early Identification and Intervention Programme at two primary health clinics run by the local authority. The clinics already had routine screening programmes for children when they came in for immunisation with their parents. The personnel at the clinic interview the parents about the child's development to determine if the child had reached appropriate milestones. However before we started our project, there was no follow up mechanism in place if problems were identified.

To change this, we developed an assessment programme for all children from birth to six years old based on measuring holistic development. Intervention is instituted either through referral to our day clinic for implementation of

an individualised educational plan (IEP), or through referrals to other agencies to develop the child to his or her maximum potential. Over the years through our work, we have realised that many young children are at risk because their developmental needs cannot be adequately provided for using the limited resources available within the community.

Play is integrated into our work because it is vital for their development and wellbeing. Play is not an *optional extra*: it is an essential in children's lives.

The programme follows specific steps with children and other service providers:

- Early identification of disabilities, including learning disabilities
- Provision of appropriate interventions
- Empowering mothers/childminders to become proactive in relation to their children's activities
- Dissemination of material crucial to the development of young children
- To partner and network with other service providers
- To establish and maintain relevant models of child intervention programmes
- To develop lifelong learning without bias
- To make appropriate referrals
- To provide an after school intervention programme

Fig. 3: All children have the right to play

## Progress to Date

So far we have identified a large need for our services and have assessed 2,502 children at the two clinics. The target group is children from impoverished communities, as well as children with disabilities. Looking at interventions according to each intervention, our progress to date includes:

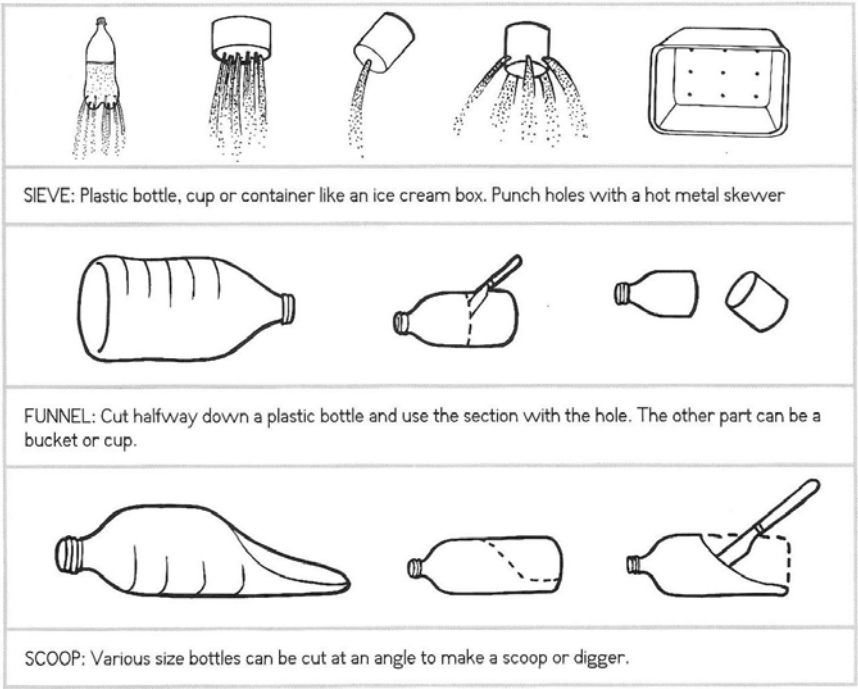
- 256 children with learning disabilities, or who were struggling at school, received assistance in the after school intervention programme
- 62 children were referred for orthopaedic interventions
- 240 were sent for speech therapy
- 36 were referred to special schools
- 42 were referred to the dietician
- 36 were referred to the Department of Home Affairs for I.D. Documents
- 21 received intervention by our in-house physiotherapist
- 4 children were sent to Sherwood Assessment Centre for Behaviour Modification interventions
- 41 parents were sent to the Department of Social Development-Counselling

This programme has been very successful as many families have benefited from it. Children who have been struggling at school, most of whom have had no access to early childhood development services, have received assistance at our after school programme and are coping better at school now. Parents have gained information and knowledge with regards the stages of development that are appropriate for each age.

Examples of the materials we use for the assessments of developmental milestones, as well as photographs from our day clinic, are shown below.

- **Sand pit toys or tools**

  Tools include buckets, spades, yoghurt cups, tins, sand moulding shapes, pieces of wood, planks and so on. Toys such as wooden or plastic trucks. Children like to add sticks, leaves and objects from the environment. The sandpit might need to be cleaned out regularly or you could have a day of sifting out debris with the children. Always keep a sandpit covered when not in use.




## Staff Training

Effective staff training is necessary for programmes to be implemented appropriately. We provide responsive, flexible, and quality training programmes because we believe that by giving a wide range of learning options we equip our staff with the knowledge, skills, values, positive attitudes and the competencies required to improve children's quality of life. In this way not only will the chil-

dren in the different programmes benefit but also the training has a far-reaching impact on the staff, who have developed their own capacity.

## Parent Training

Parents' own marginalisation, disempowerment and lack of resources significantly weaken their capacity to advocate effectively for their child's right to inclusion. Yet parents are the key to change because ultimately it is their commitment, love and dedication that will influence whether or not a child survives and develops, and whether their right to social inclusion will be respected. We have recognised the importance of empowering parents to care and campaign for their children and ensure that they have their rights monitored and uplifted. Parents are encouraged to become the extension of the teaching and learning programme so as to increase the child's opportunity for development**.** Parents can use very simple interventions to help their children, such as making toys out of discarded household items as shown in the diagram above.

Fig. 5: All parents can help their children

## Training for Inclusive Education

In any classroom or learning environment children have different characteristics, learning abilities, preferences, backgrounds, and come from different cultures. It is therefore important for educators to offer children a wide range of learning experiences to meet their different learning needs. Schools now need to develop accessible learning environments and educators need to learn and develop good teaching strategies for children in their classes so that each of the learners in their class can experience the best possible education.

To this end we provide educator training to other networking partners, and are part of the KwaZulu-Natal Inclusive Education Project consortium (KIEP), through which we provide training to the Kwa-Zulu-Natal Department of Education so that educators can welcome all children. We have also conducted workshops at five schools with learners about inclusion and how they should be able to accept all learners. Learners were shown how we all have barriers and how we can help one another in overcoming barriers. We will continue to provide training to implement change and all too often such changes have failed because insufficient attention has been paid to the needs of those who are expected to put change into effect.

## Mainstreaming

All children have a right to education, but despite this constitutional right many children are denied access, marginalised and not accepted in mainstream schools. There are relatively few integrated learning environments where all children can learn together without bias. Very few schools include children with disabilities as many schools do not facilitate mainstreaming. However through one of the schools close to Cheshire Home, Fairhaven Primary, we engaged in discussions with the principal about accepting his very first learner with disability. This

Fig. 6: A disabled child in a mainstream school

exercise proved to be very fruitful and Khethela was accepted into Grade R. The learners at the school then participated in a series of workshops prepared for welcoming all children. This transition was excellent as Khethela settled very well into his new environment and is now in Grade 7. This progression is clearly indicative that we need to be advocates and lobbyists for change and that changes can happen provided we share the dream, passion and vision.

## Qhakaza Cheshire Learning Centre

As an NGO working in the field of disability and early childhood development, it has been our goal to expand our services to the community, particularly in the most disadvantaged informal settlements where children may be affected by underdeveloped informal dwellings, overcrowded households, lack of access to education, poor facilities for health care, water and sanitation, and inadequate food and nutrition. We have through our programme:

Fig. 7: Very young children benefit from starting school

- Established a grade R programme for children who have received no stimulation at all at the local primary school – Dawnridge Primary (Grade R is the reception, or kindergarten year, which is not required in South Africa but is recommended to prepare young children for grades 1–9, which are compulsory. Grade R is sometimes also known as grade 0.)
- Provided nutritious meals to the children
- Provided children with a range of resources that are exciting and relevant to their development.
- Developed networks and partnerships with the broader community

## Conclusion

In conclusion we believe that there have been dramatic changes within the government with regards to service delivery for inclusive education. This now provides us with a challenge, as it now becomes necessary for learners with disabilities to be identified, assessed and then supported and incorporated into relevant programmes according to their needs, abilities and talents. We therefore will need to provide particular expertise and especially support in curriculum development, assessments, early identification and intervention that is appropriate and relevant to the needs of all children. There is always a sense of urgency in those who can affect children's lives for the better because childhood is too short. We must promise all children the opportunities they deserve now.

The Nobel Prize winning Chilean Poet Gabriela Mistral wrote of the child:

> "Right now is the time his bones are being formed, his blood is being made, and his senses are being developed. To him we cannot answer tomorrow, his name is today."

So as we sit here today – writing and read about the lives of young children. It is through engagements like these that we are able to share ideas and resources on meeting early childhood development challenges: let us all join hands in making tomorrow better than today.

I would like to conclude with the words of Kofi Anan: "Can there be a more sacred duty than our obligation to protect the rights of a child as vigilantly as we protect the rights of any other person? Can there be a greater *Test of Leadership*

than the task of ensuring these freedoms for every child, in every country, without exception.”

# Challenges and Solution Strategies for Early Identification and Early Intervention in the Framework of CBR Programs

*Roelie Wolting*
Dutch Coalition on Disability and Development

## Introduction

Under the UN Convention on the Rights of Persons with Disabilities (CRDP) governments must provide "early identification and intervention as appropriate and services designed to minimize and prevent further disabilities, including among children and older persons". Also the Committee on the Rights of the Child (CRC) recommends that States Parties establish systems of early identification and early intervention as part of their health services. Very often, disabilities are not detected until quite late in a child's life. The earlier intervention can start the more effective treatment and rehabilitation is.

In my own experience it is common in CBR (Community Based Rehabilitation) programs, even if they focus on children, that the majority of the children benefiting from the program are over five years. Early identification requires high awareness among health professionals, parents, CBR workers and others working with children. When CBR programmes become known in communities, and disabled children become more visible in society, the number of young children within the CBR program usually increases.

Picture 1

My first experience as a trainer was a training about early identification and intervention. This was in the early nineteen-nineties in Indonesia. During that time I learned about Community Based Rehabilitation in Indonesia. I became part of a team, developing CBR training material. Being a physiotherapist, specialised in child rehabilitation, I was responsible, among others, for the development of training material on early detection and intervention in early childhood development. For decades in Indonesia there has been the system of the Pos

Yandu for checking the health and growth of children under five years of age, in conjunction with providing vaccinations, advice on nutrition and the place for information about and registration for family planning.

Pos Yandus are in every village and every ward in the city. The women responsible for the Pos Yandu know all people in the neighbourhood. The challenge was to include early detection and intervention activities within the existing Pos Yandu program. Most activities of the Pos Yandu take place in a corridor or at the home of one of the women, full of mothers with one or more children. It is not easy to add checking the development of children as well in such a busy and noisy environment. I didn't see children with visible disabilities coming to the Pos Yandu, the few times I attended a Pos Yandu, probably because of stigma and shame around disability in Javanese culture.

We offered training to people working at some Pos Yandus, but it did not become an integral part of the Pos Yandu program. We also developed a poster with pictures of the main developmental milestones of children, to be displayed in public places, for parents to learn about the development of their child. We realised we were not able to train people from all Pos Yandus, but were dependent on the motivation of the leader of the Pos Yandu, because early detection and intervention was not within the official mandate of the Pos Yandu. Another weakness was that there was not a proper referral system in place.

The CRPD and the CRC Committee make clear statements about early identification and intervention systems. In October 2010 the new CBR guidelines, which could be the strategy to implement the CRPD, were launched in Abuja, Nigeria. In two of seven booklets of the new CBR guidelines, Health Component and Education Component, information on early identification and intervention can be found.

## Early Identification and Intervention

Early identification and early intervention in the context of this article is only about early identification of disabilities in young children, in general under five years of age. Early intervention should follow when impairment is detected. It does not specify one kind of disability, but is about identification and intervention regardless of the disability of the child.

Early identification and early intervention comprises:

- System to check young children for signs of disability
- Referral to appropriate health services for diagnosis or further treatment
- Working with young children who are slow in development or have impairments
- Educating and teaching families

The system to check young children is not only the system to check newly born babies for signs of disabilities (e.g. checking if the child has a club foot or has Down syndrome); it includes a system to check regularly the development of children in different areas of development (physical, speech and language, cognitive, social and emotional). Early identification, followed by early intervention activities, will provide much better chances to develop the abilities the child has. And it also supports the parents in taking care and supporting their child to participate and include the child in family life as the other children in the family. Inclusion of children with disabilities in regular programs and activities should be the norm. It should start within the family, but also children with disabilities should be included in all programs and facilities for young children, such as nurseries, early childhood development programs and kindergarten.

The need for an early identification program is clear. It should also be clear that early identification without an early intervention program in or near the community where the child lives and without a proper referral system is not acceptable. A system to identify children by referring to the pediatrician in a (nearby) hospital for diagnosis, who at best explains to the parents if the child has an impairment and what the impairment is, maybe indicating possibilities for treatment (e.g. to a child rehabilitation center far away and which the parents cannot afford) leaves the parents with a label for their child, but not with support. Unfortunately, it regularly happens that parents are sent home with the message that the doctor cannot do anything for their child (which means s/he cannot cure the child) without referring the parents to someone, e.g. a CBR programme, to support them in how they can help their child to develop, with the risk that parents spend (= loose) a lot of money, shopping to other doctors hoping for a cure and treatment.

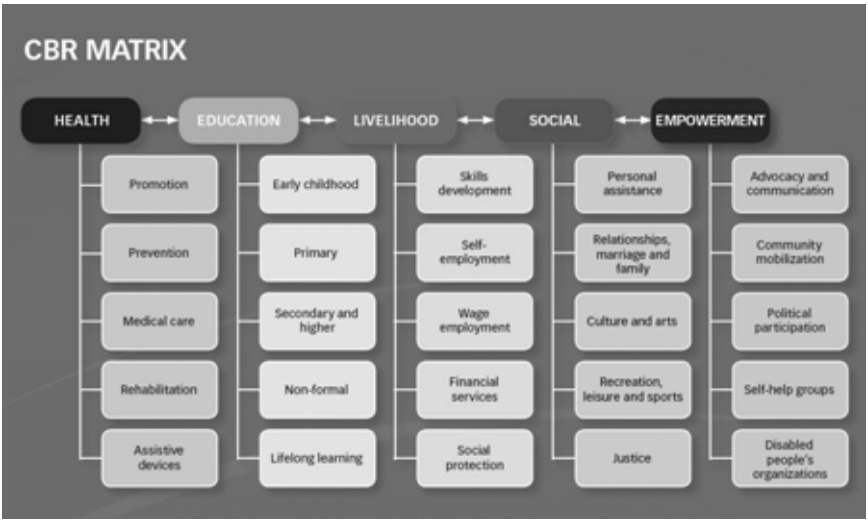
## CBR Guidelines and Early Identification and Intervention

In October 2010 new CBR guidelines were launched by the WHO, ILO, UNESCO and IDDC. CBR is a strategy towards inclusive development. The main principles of CBR are participation, inclusion, empowerment, sustainability and accessibility.

The Community Based Rehabilitation guidelines:

- Provide guidance on how to develop and strengthen CBR programmes;
- Promote CBR as a strategy for community based development involving people with disabilities;
- Support stakeholders to meet the basic needs and enhance the quality of life of people with disabilities and their families;
- Encourage the empowerment of people with disabilities and their families.

The CBR matrix gives an overall visual representation of CBR. The matrix illustrates the different sectors which can make up a CBR strategy.




Picture 2

It consists of five key components (horizontal), each divided into five key elements (vertical). Each of these elements has a chapter dedicated to it in the guidelines.

The guidelines are presented in seven separate booklets:

**Booklet 1**: the Introduction: provides an overview of disability, the Convention on The Rights of Persons with Disabilities, the development of CBR, and the CBR matrix. The Management chapter: provides an overview of the management cycle as it relates to the development and strengthening of CBR programmes.

**Booklets 2–6**: each booklet examines one of the five components (health, education, livelihood, social, and empowerment) of the CBR matrix.

**Booklet 7**: the Supplementary booklet: covers four specific issues, i.e. mental health, HIV/AIDS, leprosy and humanitarian crises, which have historically been overlooked by CBR programmes.

It is interesting to know what the CBR guidelines write about early identification and early intervention of children with disabilities, especially because it is suggested that the CBR guidelines could be a practical strategy to implement the CRPD. Dr. Etienne Krug, Director of the WHO Violence and Injury Prevention and Disability Department said, "the Guidelines on community-based rehabilitation provide an important additional tool to implement the Convention on the Rights of Persons with Disabilities and strengthen community-based development involving people with disabilities."

In two of the booklets the topic of early identification and intervention is mentioned: in the Health Component and in the Education component.

## Early Identification and Intervention and Health

Under the *chapter of prevention*: CBR programs should ensure that the training programs for traditional birth attendants, operating in the local communities, include information on disabilities and early recognition of impairments. And families should be encouraged to register children with disabilities with the local authorities at birth.

Under the chapter of health care:

Medical care refers to the early identification, assessment and treatment of health conditions and their resulting impairments, with the aim of curing or limiting their impacts on individuals.

Picture 3

Health-care personnel have an important role to play in the early identification of conditions that can lead to impairments. It is important that all health conditions are identified and treated early (secondary prevention). Some health conditions, if left untreated or uncontrolled, can lead to new impairments or exacerbate existing impairments in people with disabilities. Early intervention is less traumatic, is cost-effective and produces better outcomes.

CBR programs can assist with early identification by:

- establishing a mechanism for early identification of health conditions and impairments associated with disability in partnership with primary health care personnel;
- identifying people with impairments in the community who may benefit from surgery.

Through partnership with the medical health service CBR programs can request medical services to provide education and training for CBR personnel so they are able to assist with early detection, provide referrals to appropriate services and provide follow-up in the community.

In the *chapter about rehabilitation* some sentences are written about early intervention, especially in relation to developmental delay. CBR programs can provide early intervention activities for child development. Through focused rehabilitation intervention developmental delay can be prevented or improved. The presence of a disability, e.g. cerebral palsy, blindness or deafness, can result in developmental delay and restrict a child's ability to participate in regular activities such as playing with other children and going to school. CBR personnel can provide early intervention activities, usually home-based, to encourage simple and enjoyable learning opportunities for development. CBR programmes can also encourage parents to get together to share ideas and experiences and

facilitate playgroups, so their children learn to play with other children, learn new skills and improve in all areas of development.

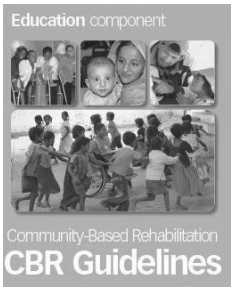
In general, not specifically for children, CBR personnel should initiate referral for specialized rehabilitation services. This includes identifying referral systems available at all levels of the health system.

## Early Identification and Intervention and Education

Early childhood covers the time from birth to the age of eight years. The chapter in the education component about early childhood care and education mainly focuses on the age of 3 years and older. For activities before the age of three, referral is made to the health component.

In the education component CBR workers should:

- Understand the importance of play
- Provide age appropriate activities
- Support families in making choices
- Work towards inclusive early childhood education provisions
- Identify early childhood needs
- Support early learning at home
- Involve families
- Promote home-based activities
- Support learning in the community
- Help develop inclusive preschools
- Ensure specialist services are available and accessible
- Involve adults and children with disabilities
- Carry out training and awareness-raising
- Address poverty
- Lobby and advocate for inclusion
- Prepare for emergency, conflict and refugee situations



Picture 4

This captures more or less what is written in the CBR Guidelines in relation to early identification and intervention. Although many good things are being said, I only can conclude that the complexity of early childhood disabilities is not enough taken into account. The need to include children with disabilities in

existing programs, like nurseries, early childhood development programs and kindergartens is mentioned, but needs more practical guidelines on how to implement and it needs discussion on what capacity is needed for the CBR worker as well as what kind of support is needed for the child focused programs.

In Vietnam the government has a national CBR program and an inclusive education policy. Lacking is, among others, early identification and early intervention services. UNICEF and the Government of Vietnam carried out an assessment of laws and policies in Vietnam in order to align them in conformity with the CRPD. The report takes an especially close look at those which affect children with disabilities.

Some conclusions of this report are:

There is a lack of early identification and early intervention services, community-based rehabilitation, and quality health care services for children with disabilities in their communities in Vietnam. This lack of services is due to inadequate funding, poor implementation, expansion, and lack of maintenance in many communities. Often health care staff does not receive adequate training, or they do not have an incentive to work with the families of children with disabilities. The right to special and free health care in Vietnam is included in many different laws. However, many children are not diagnosed early on and do not receive the services they need.

## Early Childhood – Disability – Culture and Religion

There are different understandings of a child's early years, depending on local tradition, religion, and culture. There are also different ways in which early childhood education, kindergarten and primary education is organized. The value and importance of play for children is understood differently in different cultures. Playing is sometimes seen as a waste of time or only for recreational purposes. Active learning and the acquirement of problem solving skills through play and its motivational stimulus are not part of the educational approach in many countries. These different cultural aspects are important to acknowledge when thinking about early intervention. Rehabilitation and early intervention can be associated with doing exercises, instead of stimulating development

through play. Capacity building of health workers or CBR workers should include learning the value of play.

Another important aspect with regard to early identification of disabilities and culture is the way people cope with sad news. It goes beyond this article to go into depth into this issue and the consequences it may have on how to tell and explain to parents about the disability of their child.

A few examples: A child grows up and after a few years the parents realize the child is different from other children. For the health worker, who is also active in a CBR program it is immediately clear it is a child with Down syndrome. The visual features of Down syndrome in this child are not very distinct; otherwise the parents would have realized themselves earlier. It had already been clear to the midwife though, when the child was born, but she did not tell the parents. She did not want to give sad news to happy parents. They think that waiting till the parents realize themselves is early enough for them to know. But a lot of valuable time has elapsed, without the stimulation the child needs to develop its abilities; and misunderstanding and frustration by the parents can cause early problems in building trust and relationship and self-confidence. Often the impairment is not clear immediately after birth. When a child is not developing and does not learn to sit and stand up it happens that parents just let the child and do not go anywhere for advice. This can be ignorance (they think nothing can be done and/or it will be too expensive) or shame (nobody should know).

Many people know stories about parents who go from one doctor to the other, hoping for a cure for their child. It is common that doctors tell parents to go home with their child, because they cannot treat the child. Maybe doctors mention briefly the diagnosis without explaining what it means. In some cultures, speaking words such as *delay disability* out loud is perceived as actually bringing misfortune (or curse) onto the child and endangering the child[1].

## Conclusions

Early identification and early intervention are important to facilitate the development of the child as early as possible and to develop his/her abilities. Early identification is also important in order to support inclusion in all family activi-

ties and to provide support to the parents, as well as to promote inclusion in other activities and services for young children, whether it is in the vaccination program, in early childhood development programs or in nurseries and kindergartens. Early childhood development programs usually do not include children with disabilities. Young children with disabilities are usually at home and not included in nurseries and kindergartens. Many children in countries like Vietnam go to nursery/kindergarten at an early age. These are the places to start with inclusion. It is important not to wait until primary school age, when children with disabilities, if not included in kindergarten, will start with a heavier delay.

Little is written about early identification and early intervention in the CBR Guidelines. They give some guidance on this issue, but it lacks urgency. An early identification system, although important, should not be part of a CBR program implemented by a (small) non-governmental organization (NGO), because of sustainability issues. It should become either an element of an existing system, like it could become in the Pos Yandu in Indonesia, or it should become part of the health system of a country. Early identification should never be a program on its own. Links with specialist services and with CBR services should be established at the same time as the early identification activities start. Nor should an NGO start an early identification program, when only referral is made for children with a certain kind of disability and when there is no referral system for children with other kind of disabilities. CBR programs, seeing the need for early identification and intervention, can be easily stimulated to do something to identify children with disabilities, e.g. through media or through a survey. The risk is that not enough thought is given on what should happen after identification, where to refer to and how the own program can support new children with disabilities.

Early intervention also includes the cultural and religious aspects of how to support parents to deal with the fact that they have a child with a disability. What is the impact of the CBR program on the attitude of the community? What are the support mechanisms in society? What do play, development and learning mean? Capacity building of CBR workers and parents is crucial in early intervention programs. Early identification in combination with early intervention

promotes inclusion of children with disability in family life and in the community from early age.

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## Summary of Workshop Results

# Challenges and Solution Strategies for Early Detection and Early Intervention in the Framework of CBR Programmes

Ms. Wolting first took a closer look at the new WHO CBR Guidelines which had been launched in October 2010, examining them regarding their content related to Early Detection and Intervention. The result of her text analysis is that elements of Early Detection and Intervention are mentioned in three chapters of the CBR Guidelines (Health Component, Education Component, Empowerment Component), and this is already a good start. Her recommendation is that there should be a stronger focus on Early Detection and Intervention in a next review or supplement to the CBR Guidelines. Ms. Wolting's own starting point on this subject in her professional career was the discovery she made many years ago that the youngest age group of children was almost not visible in CBR projects, making her wonder about the whereabouts of the disabled children below five years of age.

After Ms. Wolting's inputs the discussion of the participants of this workshop focussed on one hand on the *Challenges* faced for spreading Early Detection and Intervention by means of CBR, and on the other hand on elements *Necessary for Success*.

First an overall guiding question complex was formulated:

Can Early Detection and Intervention be mainstreamed into General Early Childhood Development (ECD) Programs, and can CBR be an instrument to achieve this?

The overall challenge is how to take the step from CBR to Inclusion/Mainstreaming. As a possible strategic step towards this objective a joint symposium on CBR and ECD was proposed.

As further challenges or obstacles for Early Detection and Intervention within CBR-programs were indicated:

- CBR is often understood too narrowly
- Orientation on big donors can be an obstacle

- How can attitudes of Government Education Authorities be changed?
- There is often lack of child registration
- Simple tools are not available
- Distances and bad roads in rural areas
- Lack of referral system
- Cultural perception of disability
- *Sector approach* to different types of disability (instead of focussing on all types of disability in a certain area)
- Restricted attitude regarding the roles of women/mothers
- Lack of self-help attitude; too much dependency
- Lack of understanding regarding *Play* (as a good and child appropriate means of early intervention)
- From which level should volunteers come?
- How can training be effective? (Who can train whom? To which extent?)
- Lack of follow-up after initial training

As elements necessary for success the following were collected:

- Sensitize communities for needs of all people living in the community
- Strive for collaboration between NGOs and Government authorities
- Implement a social approach (*de-medicalisation*)
- Information, capacity building, empowerment through training in the appropriate way
- Search for *local champions* and *agents of change* (e.g. people who dare to raise their voice)
- Do not work with too many professionals on the village level
- Work with parents: establish parents' groups; train mothers to train other mothers

*Christine Wegner-Schneider*
Caritas international
Workshop Facilitator

# Creating New Avenues for Early Inclusion

*Usha Ramakrishnan*
Vidya Sagar, Chennai

## Introduction

Every child is a miracle, born with a unique potential and entitled to human rights: the right to survival; to develop to the fullest; and to participate fully in family, cultural and social life. This is applicable to all children everywhere.

Some children are born in environs that enable them to enjoy these rights; they are nurtured with love and they develop their potential. Unfortunately this is not the case for all children. As the UNCRPD[1] states in its preamble children with disabilities are often unable to develop their potential or access their rights because of attitudinal and environmental barriers and the discrimination they face from birth.

This is a matter of concern as early childhood years (birth to six) are critical for development. Children with disabilities have the same rights as other children. They need equal opportunities to play and learn in the early years, in a way best suited to their individual profiles.

A child's potential and holistic development is enhanced when there is effective child care, with the caregiver's awareness of the importance of the early years and good parenting practices.

While early positive experiences enable lasting feelings of self esteem and self worth *negative* early experiences of prejudice and exclusion can leave indelible scars on the psyche, that last a lifetime.

Often lack of awareness of the importance of the early years, lack of support from the community and the absence of good parenting practices are responsible for the child's underdevelopment. Enlightening and empowering the parent is the first step towards a child's potential being realized. Supporting and enabling the community workers in early childhood programs is essential for this.

## The Need for a New Perspective

Children develop their potential when *all* areas of development are considered and nurtured holistically. A child's sense of self, physical development, rela-

tionships, understanding and communication form the different areas of development. They are interconnected and equally important and weave together to form the child's personality. This includes children with disabilities.

It is a matter of great concern that when a child has a disability the focus is mainly on the disability, and on *normalizing* the child. Children with high-risk birth histories may have an uneven developmental profile, lagging in some areas of development, while doing well in others. The child's strengths remain unnoticed and untapped. The child gets slotted into the lowest level of attainment rating among various areas of development. There is a need to look at special children also holistically.

**In a Typical Scenario**

The emotional well being of the child with disability is least understood and therefore, given scant importance. The child remains passive, with self esteem thwarted even as he is excluded and kept apart….

The child's abilities in other areas may lie hidden beneath the more obvious disability. As persons with disabilities themselves say: "Just because I cannot walk, it does not mean I cannot think", or: "Just because I cannot speak, it does not mean I have nothing to say". Abilities need focus and attention, for they contribute vitally to the child's self-esteem, the core of a personality.

Parents of children with special needs may be lost, stressed and overwhelmed with the disability.

They may be totally dependent on professionals for guidance. They need to feel as equal partners with professionals when dealing with their children, even as they seek information, support and guidance from them. Disability tends to be mystified by the medical model. There is a need for the human rights approach as spelt in the UNCRPD.

Community workers who are with early childhood programs may not understand disability especially when it has been mystified. They may not feel confident with skills and knowledge to include children with special needs; this may affect their attitude to inclusion. They need to feel comfortable and confident to the task of early inclusion.

In this conference, we present a tool that makes it easy for the community and individual families to understand and include children with their differ-

ences, in general early childhood programs, appreciate them for their special abilities or needs and help them to achieve their potential. The tool helps to focus on the psycho social well-being of every child and helps us to better understand and accept the diversity we see in children. It enables us to view and nurture the child holistically and is inclusive of all children.

The *Parenting the Child Accepting Diversity* package helps look beyond children's disability or special need to find their abilities identify the child's unique profile and effectively support development. It is designed to empower parents and caregivers with knowledge that their child can be different yet equal and be active partners in the planning of the child's program. The package enables professionals to share expertise and skills with parents, caregivers and workers in the community.

The Package *Parenting the Child: Accepting Diversity*, comprises the Quadrant, the Oval and the *Learning through Play* calendars and a user manual. The Quadrant and Oval formats are support materials designed to be used along with the calendar. They enable the user chart out a holistic profile of the child and plan management strategies.

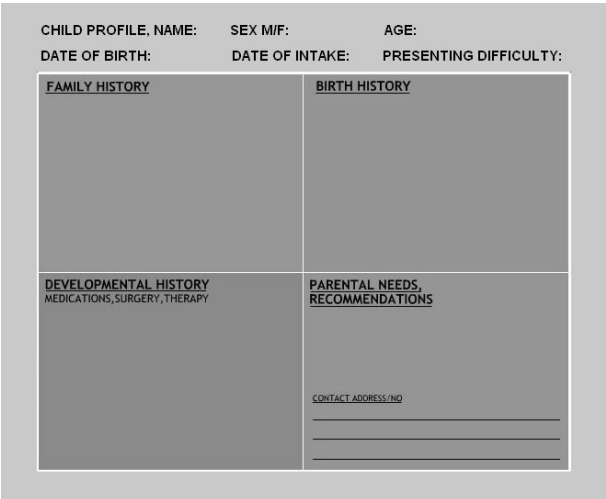


Fig. 1

The Quadrant - with four segments is designed to facilitate recording in one page important information regarding a child's family, birth and developmental history and parental needs. When considered together they provide holistic information on the child's background.


Fig. 2

The Oval Format with 8 segments has been designed to form a holistic profile of a child.

To record a child's current performance levels in various areas of development,[2] both abilities and special needs. When filled completely it shows priorities be worked on, management and intervention plans holistically. The user manual guides step by step through the process.

**The Learning Through Play Calendars**
**Birth to Three, Three to Six Years**

The *Learning through Play* Calendars are a resource for parents, enabling them to discover enjoyable ways of nurturing and playing with their child at different stages of development from birth to six years[3]. The calendars pictorially, represent with simple, clear, messages, a child's important developmental stages and needs from birth to six years. They focus on all-round development and follow a child as her sense of self; physical skills, relationships, understanding and com-

munication develop. The calendar is an excellent parent education resource, presenting in pictures a range of activities that parents can do with children, to promote holistic and healthy development.

Salient Features

- Designed by experts in child development as a parenting resource
- Explains current research findings in simple messages and pictures
- Demystifies child development
- Focuses equally on all areas of development including the vital and least understood sense of self
- Explains needs from the child's perspective
- Explains what when how why and where parental support is needed. Empowers those in a parenting role
- Is in keeping with the Theory of Multiple Intelligences[4]
- Has been translated into various languages
- Allows for individual profile to emerge

Bala Mandir Research Foundation, Chennai, India, in partnership with the Hincks Dellcrest Centre used the calendar for parent information in various socio economic settings. The move to applying the tool with families and professionals working with children with special needs was an obvious and exciting next step, undertaken by the Foundation.

## Adapting the Calendars to Include all Children

Further to a study project, the calendars were adapted and reformatted to include children with special needs. In two sets, each calendar covers 14 stages from birth to six years.

Calendar 1 with 14 stages depicts the child's development at each age (two months, five months and so on). Each page illustrates the normative development at that stage with salient features and messages of how learning occurs through play. The pages are color-coded to match corresponding stages in Calendar 2.

Calendar 2 also has 14 stages, but with a reference to stage instead of age, in order that parents could see the sequence of development, rather than focus on age norms. The stages are color- coded to match corresponding stages in Calendar 1.

Each of the 14 stages contains in five columns, messages and pictures illustrating the development of the child's sense of self, physical development, relationships, understanding, and communication. In the adapted version, the five columns are segmented to be independent of each other across the 14 stages.

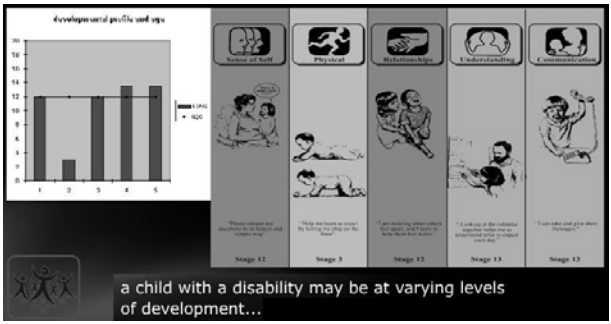


Fig. 3

This reformatting allows for multi-segmentation of the developmental profile and for an individual holistic profile to emerge, where a child can be at different developmental levels in the different domains. The profile obtained enables attention to be focused appropriately on the five segments individually. To make it user- friendly and inclusive, some of the illustrations were modified, to include children with disabilities.

**Benefits of the Calendar**

The calendar is able to convey complex principles of development and explain the interaction between learning and the environment available to the child. This makes it the ideal bridge for professionals to reach families and other adults who regularly interact with the child. Several features of the calendar are found effective in reinforcing a more holistic way of looking at the child with special needs.

**Holistic Perspective**

The calendar depicts all areas of development; the segmentation of each domain allows the profile of the child to emerge, helping the user to keep the child's

abilities in view, while noting areas where support is needed. The individual profile serves as an interaction guide for the adult.

For many parents, seeing their child's abilities highlighted so clearly makes them more positive about their child's potential. For experienced as well as new professionals, typically trained to look for areas of delay and impairment, it enables a shift in perspective from a focus on disability to an appreciation of the child's abilities.

**Ease of Understanding**

The illustrations and easy-to-understand comments make it accessible to people from a variety of educational and socio-economic backgrounds. The calendar can even be used with siblings, to help them understand why their brother or sister behaves in certain ways and what they can do to help. The illustrations suggest activities appropriate for the child at a given stage. This opportunity for self learning, which the calendar provides is both unexpected and powerful. It demystifies intervention for children with special needs into simple, typical child-rearing activities. It also places information in the hands of the parents and workers with little formal training, whose interactions have a substantial impact on the child.

In each picture, the voice of the child tells the adults how their actions can support the child's learning and development. The message that much can be achieved by changing the environment rather than changing the child is a positive one. The illustrations capture everyday activities in the home and imaginatively include adults and siblings to highlight the importance of the social and physical environment. The activity ideas that emerge are easily incorporated within the child's natural routines and environment.

**Conclusion**

In one simple move of segmenting the columns of the calendar, a new vista has opened, enabling a child's unique profile to appear. *All* children will be understood in a different perspective, and appreciated for their special abilities or needs, and helped to achieve their potential and be included in general early childhood programs.

The package also enables the professionals to demystify disability, while conveying information and skills to the parent or community worker. The pictures and the messages speak the *thousand words* that empower the parents or care giver with the knowledge that their child can be different – and equal. It enables a parent and community care giver to be a proactive partner in the planning and execution of the child's activities. The attractive pictures make it user-friendly even for the unlettered. This adapted calendar is sure to produce a paradigm shift in the way a child's development is studied and assessed.

## Notes

1 United Nations Convention on the Rights of Persons with Disabilities...preamble: "disability is an evolving concept and disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others,"
"persons with disabilities are subject to multiple or aggravated forms of discrimination on the basis of race, colour, sex, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, birth, age or other status."

2 Areas of development: emotional - Sense of self, Physical (health, sensory areas, self care, motor), social Relationships, Understanding Communication (SPRUC)

3 The original calendars were designed by experts in the field of child development from the Hincks Dellcrest Centre Toronto, Canada, in collaboration with Toronto Public Health, Babies Best Start Program, Toronto, and Aisling Discoveries Child and Family Centre. It was based on the earlier work Good Beginnings by Judith Evans, and revised to reflect current research findings.

4 The theory postulated by Howard Gardner says different people are intelligent differently: "It's not how smart you are it is how you are smart". The Intelligences Linguistic, Logical Mathematical, Musical, Spatial, Bodily Kinesthetic, Naturalist, Interpersonal and Intrapersonal Intelligences are the multiple intelligences. Different people have different profiles of a combination of the intelligences. They can also be present in isolation.

Figures 1&2 courtesy Usha Ramakrishnan

Figure 3 courtesy Adapted Learning through Play Calendar

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# Development of a National Model for Inclusive Early Education in Chile

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## History of the Model

The model was first developed at an institution aimed at integrating children with disabilities which had been in operation since 1995, i.e. on the basis of a sound foundation of practical know-how and sensitivity. The GTZ (German Technical Cooperation) Project was able to revitalize the model and to shift the emphasis from integration to inclusion, a major change in paradigm. Eventually, the model become part of the Chilean Integrated System for Child Protection (2006-2010) as illustrated in Figure 1.

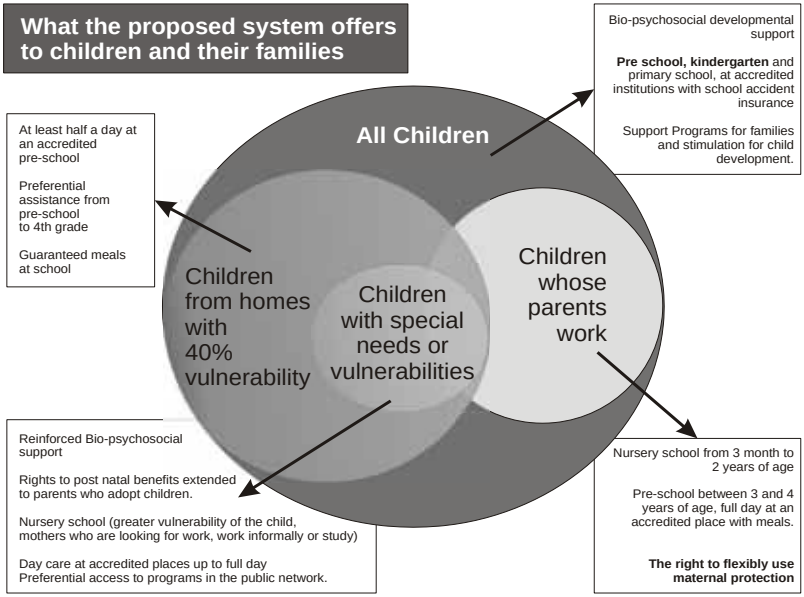


Figure1: Diagram illustrating how the model is integrated into the Chilean System for Child Protection.

## Chile: Some Numbers

Since 1990 and throughout the following two decades, poverty and extreme poverty have decreased significantly in Chile. Although the 2010 earthquake did have a negative effect on poverty indicators, other indicators are still generally good: low levels of infant mortality, good health indicators, significant rise in life-expectancy, high level of urbanisation, high levels of schooling. Currently, one out of three children between 0 and 5 years of age receives early education.

It is estimated that more than 18 thousand children between 0 and 5 years have a disability. This condition is more frequent among people living in poverty: one out of five, compared to one out of 21 people of high socio-economic status. These numbers clearly show a close relationship between disability and poverty.

## Project Interventions

The Project involved the planning and implementation of interventions at different system levels:

- *Macro Level*: impact on early education policy through the incorporation of inclusive education in the Curricular Reference in all early education institutions. Simultaneously, a university and NGO network was developed.
- *Meso Level*: the disability *approach* or *view* was included in the technical and administrative work of the National Bureau of Nursery Schools (JUNJI is its acronym in Spanish).
- *Micro Level:* impact on professionals, experts and relatives involved in the JUNJI nursery schools, due to substantial increases in coverage as well as the effective and sensitive support by the staff.

## National Bureau of Nursery Schools (JUNJI)

In Chile, this State institution provides early education under a holistic approach that includes education, nutrition and health. The specific issues associated with indigenous peoples, poverty and gender are part of its daily work. With 40 years of existence, the JUNJI is currently in charge of 1,700 kindergartens that receive some 150 thousand vulnerable children. Of these, 2,800 were children with

disabilities in 2010, compared to 1,433 in 2007, showing that coverage has indeed increased under the GTZ Project.

The key aims of the JUNJI are coverage and quality in addressing the needs of the poorest 40% of the country. Focusing on women who work or study, its function is critical in the improvement of early education in Chile.

In Chile, integral pre-school education for children under six belonging to poor or extremely poor strata is established by law since 1970, including education, stimulation, health care and proper nutrition. Figure 2 shows the integrated approach to pre-school education applied in Chile.

In 2008, the then Director of Budget of Chile declared: “Investment in pre-school education is characterized by its impact on several dimensions of social protection” (Alberto Arenas: “Educación Parvularia: Una inversión donde se conjugan todas las rentabilidades", paper presented at the international seminar "El Impacto de la Educación Inicial" Junta Nacional de Jardines Infantiles. Noviembre 2008).

The contribution of pre-school education to the improvements in the educational and social indicators Chile has experienced is the reason why it is currently so valued there.

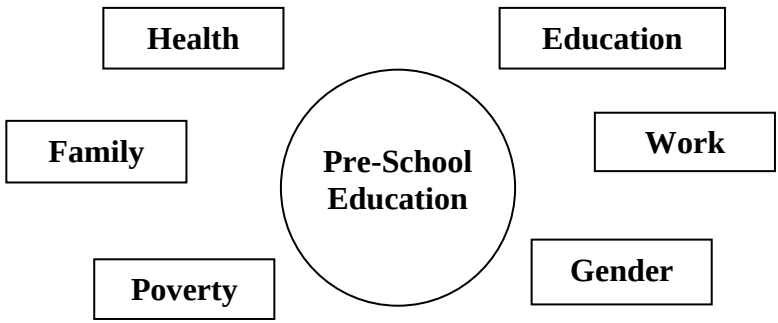


Figure 2: The integrated approach to pre-school education applied in Chile.

**Design and Implementation of a Model of Inclusive Early Education**

Between 2007 and 2011, the GTZ Project aimed at implementing a model of Inclusive Early Education, for which it defined the following indicators of success:

- Quality: 40 % of children with learning difficulties in JUNJI have been evaluated and had increased their learning results at the final evaluation by the end of 2010.
- Coverage: In 2008, the coverage of children with learning difficulties rose by 5% compared to 2007, and in 2009 15% compared to 2008. By 2010 there were 2,800 children with disabilities being received by the JUNJI.
- Capacities of parents to be strengthened, so that they are supportive of their children with learning difficulties. These indicators are still being processed.
- Policy: By the end of 2009, the JUNJI had developed a model of Inclusive Early Education.

This success has been achieved thanks to a number of actions:

- Sustained sensibilization and training activities since 1995.
- Strong support of the Convention on the Rights of Persons with Disabilities (2008) and updating of Chilean law (2010).
- The work of 80 professional teams in all 15 geographical regions of Chile.
- Training. Four national training workshops with GTZ experts which were attended by 70 JUNJI professionals. Replication of training in the regions, reaching a total of 480 JUNJI professionals. Among the international experts were Dr. Maria Kron, Siegen University, and Dr. Jo Leber, Director of INCLUES International.
- Distribution of two textbooks that promote inclusive education for each of the 2,400 JUNJI educational units and programmes (a total of 4,800 textbooks).
- Incorporation of Inclusive Education as a key issue in the Institutional Curricular Project.

- Adjustment of the methodology used to assess the learning of children with special educational needs.
- Development of a Training Course on Mediation of Learning for the JUNJI staff (multimedia and handbooks).
- Development of a Training Course and Supporting Guide for the families of children with disabilities.
- Inter-institutional coordination: six public institutions, three NGOs, and two round tables to work on various documents.
- Academic coordination: eight universities involved in the training of nursery and special needs teachers.

The text whose cover is shown in Figure 3 is included in the JUNI´s new curricular reference, specifically addressing inclusive education (see Spanish version at www.junji.cl).


Figure 3: Cover of Support Material on Inclusive Education.

The factors that contributed the most to this success were:

- Teams of mediating agents: early education professionals committed to becoming agents of social change.
- Incorporation of the approach in all activities of the institution: vision, goals, plans, programs.
- Adequate curricula and infrastructure.
- Promotion of the view that there always are people with disabilities in the institutions who require support.
- Ensuring political anchoring of the model.

Taking into account that we are dealing with a shift in paradigm, from a medical to a social approach to disability, the requirements for a sustainable change were the following:

- Intention as a change of mindset.
- Diagnostic assessment of *support* needs.
- Hiring of professionals.
- Establishing roles and functions in common agreement.
- Permanent sensibilization and training in paradigm change and practical elements of the curriculum. Continued creation of a common understanding, e.g. *institutional language* concerning disability and inclusion.
- To train personnel in *learning mediation*. Not enough to have the child in the school: he or she must learn.
- To train staff and parents on specific needs of parents of children with disabilities.
- To hire more special teachers.
- Planning, time and space distribution, differential evaluation, inclusion of parents, community…etc.

The future plans are the following:

- To continue creating a common understanding, e.g. *institutional language* concerning disability and inclusion.

- To train personnel on *learning mediation*. Not enough to have the child in the school: he or she must learn.
- To train staff and parents on specific needs of parents of children with disabilities.
- To hire more special educators.

**What to Advise Others Seeking to Replicate the Model?**

From the experience gained so far, the following suggestions may be offered:

- To carry out a well-planned and permanent sensibilization and training programs on inclusive education for the institution: gender, ethnicity, poverty, disabilities, etc.
- To introduce the issues of diversity and people with disabilities to the training courses of the professionals training teachers
- To hire special teachers to act as support to the school teacher and the families.
- To set up the program in agreement with the senior authorities of the institution, and hopefully depending directly on them.
- Sensibilization is reinforced by interacting directly with people with disabilities: organize activities where they can participate and show their abilities.

Adaptation of teaching materials: dolls with disabilities.

# Inclusion of Children with Disabilities in Early Childhood Services and Facilities in Germany: where are we?

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Deutscher Caritasverband

The professional and political discussion in Germany on the inclusion of children and young people with disabilities is nothing new. On the subject of day-care facilities especially there was intense discussion in the 70s concerning the integration of children with disabilities.

With the signing of the UN Convention on the Rights of People with Disabilities (UNCRPD), which came into power in Germany in March 2009, however, German social policy was once again presented with new challenges. The law relating to the United Nations Convention from 13 December 2006 concerning the rights of people with disabilities is based on the central United Nations conventions on human rights and embodies the human rights established in the Convention for the lives of people with disabilities. The Convention prohibits the discrimination of people with disabilities in all areas of life and guarantees their civil, political, economic, social and cultural human rights.

Looking back into history, it should be noted that *care* for people with disabilities here in Germany has a long tradition in comparison to other countries. In the middle of the 19$^{th}$ century with the beginning of industrialisation the welfare state in Germany was already being organised. The first schools for children with special needs (Hilfsschulen) were set up and so-called *institutions for the feeble-minded* established. The church and its religious orders felt they had a particular obligation towards these people and provided them with health care, school education and work. They received all this in - mostly - sizeable institutions. Here, they were on the one hand provided for but on the other hand these were also segregated living spaces.

From 1934, however, began a dark chapter in German history. In 1934 the National Socialist regime issued the so-called Sterilisation Law, as a consequence of which approximately 400,000 people with disabilities and psycho-

logical illnesses were compulsorily sterilised. Between 1939 and 1945 at least 300,000 people were murdered on the basis of their disabilities.[1]

The development in the time from 1950-70 in Germany of an extremely specialised and differentiated system of assistance for people with disabilities has to be seen with this in mind. But even in the 60s, self-help groups were increasingly being founded in Germany by disabled people themselves - active in the area of disability policy and with the idea that disabled people themselves know what is best for them.

On the development of inclusion and on the situation in Germany there is much to report. In view of the situation - as you know I have taken over the workshop at short notice for Frau Mulder - I will restrict myself to two specialist areas. As examples I will describe the situation in the care of children under three and the state of inclusion in schools.

My choice of these two areas was based on the following aspects. The planning and implementation of day-care for under threes with disabilities is being discussed at the political and (slowly) at the professional level in Germany and the need for action is increasing.

School education is an essential element in early childhood development. Contrary to other services, school is compulsory for all children in Germany. It is precisely the first years at school that are of major significance in respect of inclusion but also as an essential element in the fight against poverty.

## Care of Children Under Three

Even today, the fundamental question of whether attending day-care facilities for children under three - with or without disabilities - should even be aimed for is discussed and answered in very different ways. For a long time, day-care facilities were seen as places to dump the kids and parents who brought their children there were said to be uncaring or even to have no sense of responsibility or skills in bringing up their children. There are opinions even today that are vehemently critical when the subject of the care of under-threes comes up. For example, in 2011 on the homepage of the – not unknown – child and adolescent psychotherapist Christa Meves, the following statement could be found on the care of under-threes: “Nursery care for children in their first three years is an

unnatural and artificial product. It has been thought up by politicians on the basis of economic and feminist demands without considering the best interests of the children. Out-of-home-care of babies and infants in a collective, which is what the nursery model represents, does not correspond to the developmental requirements of the human being and carries serious risk factors in adulthood for the children treated in this way in relation to their psychological and physical health“[2]. In her article *The Risks of Nursery Care,* she summarises her conclusions so: “Nursery care minimises in an irresponsible way the conditions sufficient for healthy development. Experiments on animal babies, for example, rats and apes, have shown that when the babies are separated from their mothers for only one hour a day they have diseased brains as adults. For the healing of our sick society we do not need nursery care, but rather, with the aim of developing a balanced brain that is able to learn and love, a genuinely natural approach of the mothers to their babies and infants, by providing mothers for this task with the possibility of devoting themselves fully to their small children“[3].

The important Hungarian paediatrician Emmi Pikler however, came to quite different results. She had very well trained carers working with clear rules, looking after thousands of children in her orphanage and later in all Hungarian orphanages. A long-term study financed by the World Health Organisation reveals that the development of the children in adult years, especially in relation to psychological and emotional development, was fully comparable to that of children who had grown up in familial circumstances[4]. Paediatricians in particular see in out-of-home-care, if there is adequate staff and facilities - a good chance as well for children who have not received adequate support in their families. Early nursery attendance can therefore contribute significantly to improving equality of opportunity for the children.

The availability of nursery places for small children however, in Germany differs hugely from region to region. Even at the present, considerable differences exist in the structure of services between the federal states in the west and the east of the country, although even within the individual states in the west considerable variance also exists between the situation in the larger population centres and rural areas. The German Federal Statistics Office records nationwide for 1.3.2009 only 1,213 facilities for children under three, and one can assume

that a needs-related and nationwide expansion even in the next few years is not to be expected.

According to the figures in the 2009 Report on Disability, at the present, only about 1,805 children under three with disabilities are attending a day-care facility. From these alone 23.9% (432 children) are in day-care facilities in Berlin, 42.8% (772 children) in facilities in the old (former West Germany) and 33.3% (601 children) in facilities in the new federal states (former East Germany).

Possible reasons for this could be:

- lack of capacity in normal day-care facilities (reduction in group sizes)
- different providers (social welfare, child and youth welfare)
- early learning measures and concurrent attendance at day-care facility - a few providers see here an overlap
- social evaluation
- (supposed) lack of expertise in the care of children under three with disabilities

The reasons of parents - including parents of disabled children - for wanting, demanding and also accepting the services of day-care facilities can be very different. The following aspects, however, are of primary significance:

- right of all family members to develop their personality
- economic necessity of both parents or the single parent to work
- positive significance of early social contact with other children for children with special needs
- individual social situation of families with children with special needs and
- wish of parents for early professional support

Attendance is seen as an important element for development and for future educational opportunities. Early childhood education and care form a significant element in respect of equal opportunities.

This is also confirmed by the results of a study by the Bertelsmann Trust. Child development particularly in the early years is especially dependent on the developmental and educational stimulation provided by the surroundings and early childhood education is a major influence on the educational path of the

child. The results show that children from families with a low educational level profit especially from early nursery attendance. The probability of attending Gymnasium (grammar school) increases from 36 to 50% if they attended nursery[5].

It can therefore be assumed that especially for children who according to the law are considered to be *threatened by disability*, early attendance at a nursery or play group is of particular importance for later development in school. This can contribute significantly to help avoid a fractured educational career[6]. It can also be assumed that a broad availability of day-care places will especially reach those children who under certain circumstances are not addressed by early learning services.

In Germany, however, an ever-decreasing percentage of children under three with disability are attending day-care facilities and there is urgent need for action.

## Integration in Schools

The right to education for people with disabilities was not first established by the UNCRPD. Article 13 of the International Covenant on Economic, Social and Cultural Rights (ICESCR) in 1966 established how educational institutions had to be structured so that they were open for everybody. The UN Convention on the Rights of the Child (UNCRC), which Germany has also signed, refers to this in Article 28. With the signing of the Convention, professionals, politicians and people affected received a new impetus.

Of particular significance is Article 24 (Education) of the UNCRPD which refers to inclusive education. Paragraph 1 stipulates that: “States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and life long learning.” The basic UNCRPD principles, which are meant to prevent exclusion, are formulated in Article 3. Of these, the following principles are of special significance with respect to inclusive education: respect for the difference of persons with disabilities and acceptance of them as part of the human diversity and humanity, non-discrimination, equal opportunity, accessibility, assisted

independence as well as full and effective participation and inclusion in society. Such an understanding means that children and young people no longer have to fit into the education system but that the state (here the education system) has to adapt its services and structures to the special needs of children and young people.

According to the education laws of each federal state in Germany, integration in schools is basically possible and - partly in accordance with the UNCRPD - integrated lessons are also expressly recommended. At the same time every federal state reserves the right to enable integrated schooling only then when the personnel, material and organisational preconditions exist at the respective schools or can be set up. This sovereignty of the federal states leads to an extremely varied picture in relation to inclusive schooling and at the same time, points to a need for action in Germany. In plain words this means that only approximately 15% of children with disabilities attend a school with children without disability. As a result, Germany compares unfavourably at the international level. In Spain, Italy and the Scandinavian countries almost all pupils with special needs attend normal schools and in Great Britain it is approximately 80%[7].

In Germany, according to the figures of the Conference of Education Ministers[8], a so-called diagnosed *special education need* was determined for 480,000 pupils at the primary and secondary levels, corresponding nationwide to approximately 6%. From these, 43.8% have learning difficulties and only 16% have a mental disability. 11.5% have emotional and social difficulties and 10.6% have a language disability. When you analyse the significant differentiation between the states, then the suspicion arises that the individual disabilities are not the exclusive determining factor but more the political will of the state governments to shape their inclusive education policy. So, for example, between the federal state with the highest rate of integration (Hamburg with 22.29%) and the state with the lowest rate of integration (Baden-Württemberg with 0.27%) there is a difference of approximately 20%[9]. At present, Germany is “open to the accusation that it is very much alone in Europe with a system of segregation for which it has to pay a high price; too many young people are left by the wayside without any school qualifications or future who we then try to get into

training programmes and work through a complicated and expensive bridging system, and too often failing in the process”[10].

In the next few years, school has to become a place of learning open to all children irrespective of their disabilities, social background and also immigrant background. Alongside inclusive school services, this primarily requires inclusive curricula and school/pre-school teacher training and in-service training to become inclusion-based. An inclusive school is a school open to all children - irrespective of their social background, possible disabilities or immigrant background - where in mixed-ability learning groups they can be supported to the best. It enables children with special needs more chance of participation and - as long years of experience have shown - inclusive lessons also have a positive influence on children without special needs and not just in the development of social skills. As countless studies in the meantime show, all children profit from the practice of individual support that is a consistent element of an inclusive school. Inclusive schools also improve the chances of participation especially for children from socially weak families and immigrant families who at the present are over-represented at special education schools.

## Conclusion

Alongside education and upbringing in the family, a special role and responsibility has to be assigned to day-care facilities and the education system in shaping the early childhood worlds of learning and living and enabling all children to have a chance to participate in society. The establishment and expansion of the age-appropriate facilities of the day-care system - especially for the under-threes - and appropriate places of learning for children with disabilities is to be seen as an important step towards fairer chances in life and in accordance with the UN Convention, realises the right to participation, support and education. Public education institutions are legally obliged to promote social, emotional, physical and mental development. Barriers in the early childhood education system have to be removed in order to enable the participation of every child in high-quality education - there is still a long way to go until Germany actually implements the provisions of the UN Convention for an inclusive education system.

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