

Global perspective on early diagnosis and intervention for children with developmental delays and disabilities

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This article is commented on by Newton on page 1072 of this issue.

PUBLICATION DATA

Accepted for publication 4th April 2012.

Published online 13th July 2012.

ABBREVIATIONS

AAP	American Academy of Pediatrics
AEDI	Australian Early Development Index
CDC	Centers for Disease Control
CFD- WHO	Care for Development-World Health Organization
HIC	High income countries
HRSA	Human Resources and Service Administration
IMCI	Integrated Management of Childhood Illness
LMIC	Low-and middle-income countries
NGOs	Non-government organizations
TDRE	Think developmentally refer early
USAID	US Agency for International Development

Low- and middle-income countries are experiencing a significant reduction in mortality of children under 5 years of age. This reduction is bringing in its wake large numbers of surviving children with developmental delays and disabilities. Very little attention has been paid to these children, most of whom receive minimal or no support. Thus, there is an urgent need to recognize that improving the quality of life of the survivors must complement mortality reduction in healthcare practice and programs. The incorporation of early evaluation and intervention programs into routine pediatric care is likely to have the most impact on the quality of life of these children. We therefore call for leadership from practitioners, governments, and international organizations to prioritize regular childhood developmental surveillance for possible delays and disabilities, and to pursue early referral for intervention.

DEVELOPMENTAL DELAYS AND DISABILITIES IN LOW- AND MIDDLE-INCOME COUNTRIES

In low- and middle-income countries (LMICs), a marked decline in mortality among children under 5 years of age has begun and is accelerating.^{1–4} This trend is clearly related, at least in part, to the achievements of world campaigns to eradicate or ameliorate the impact of HIV/AIDS, tuberculosis, malaria, and malnutrition, among other conditions. The 22% reduction in child mortality achieved thus far still falls behind the target set by the United Nations,⁵ and efforts need to be intensified to reach those goals. Nonetheless, the resulting societal changes are already profound, and these too will accelerate in coming years.

Within this increasing survivor group in LMICs, it is estimated that more than 200 million children have developmental delay or disability.⁶ The components of this enormous problem have been studied from many angles. Studies of survivors of HIV/AIDS^{7,8} and malaria,⁹ for example, show that they have a high prevalence of neurodevelopmental delays,

cerebral palsy,^{10–12} and intellectual disability.¹³ In essence, there is an emerging new population of children in LMICs with developmental delays and disabilities whose existence must be recognized and dealt with in all health practice and planning.

The obvious question is what can be done to address this quietly growing problem? First, we need to recognize that the same social environments that have a negative effect on survival also tend to increase disabilities among survivors.¹⁴ This calls for long-term primary preventive interventions that increase survival and reduce disability in tandem. For example, improved living environments and access to good quality health and social services are priorities for both objectives.¹⁵

Second, among those who survive, we need to reduce the negative consequences of morbidity events in infancy and early childhood through secondary preventive interventions such as early recognition and support. We will focus on this second component because it requires giving specific attention to early identification and intervention of developmental delay

and disability, which have been shown to affect cognitive,¹⁶ motor,¹⁷ and long-term social development positively.¹⁸ The challenge lies in identifying and operationalizing what is feasible and appropriate in different settings.

DEVELOPMENTAL DELAYS AND DISABILITIES IN HIGH-INCOME COUNTRIES

To broaden our perspective, it is important to recognize that the increasing extent of childhood delays and disabilities is certainly not unique to LMICs. Studies from the USA Centers for Disease Control, and the Human Resources and Services Administration, show that the prevalence of developmental disabilities in the USA from 1997 to 2008 was 13.7%. During this period there was an increase of 17.1%, indicating there were some 1.8 million more children with developmental disabilities in the USA in 2006 to 2008 than a decade earlier.¹⁹ Thus, even the availability of much greater resources, infrastructure, and technology does not necessarily translate into fewer children with deficits in high-income countries.

Early identification of the young child in high-income countries who has developmental delays or deficits is recognized as an essential part of good healthcare for children in regular pediatric practice.²⁰ It is strongly endorsed by the American Academy of Pediatrics,²¹ and has been consistently shown to effectively identify childhood abnormalities which otherwise are likely to have been missed.^{22–25}

Yet in the USA, for example, there is far from universal acceptance or practice of early identification and intervention, despite persistent education and promotion efforts over many years. Data are scarce about the current USA practice of regular child health surveillance in pediatric practice.²⁶ However, studies suggest that children often do not receive a periodic developmental assessment,^{27,28} fewer than half of pediatric practitioners use formal screening tools,²⁹ and only one-fifth of children received parent-centered developmental screening in a 12-month period.³⁰ Even in a trial of the American Academy of Pediatrics' early screening algorithm, among a group of well-trained pediatric practices in the USA that volunteered their time, only 61% of the children who failed the screening procedure were actually referred for further evaluation and possible early intervention.³¹

Nonetheless, much can be learned from the early efforts of high-income countries such as the UK, where the concepts of both regular developmental surveillance and early screening were initially focused through the 1976 Court,³² and subsequent Butler, and Hall and Ellman reports.^{33,34} Though over the years there have been various and often conflicting recommendations about their implementation,³⁵ these reports stimulated much clinical research in a variety of programs in which surveillance and screening formed the basis for child development activities in several countries, such as in the Child Health Promotion Programme in the UK.³⁶ The Australian Early Development Index is another example of active surveillance in which teacher identification of children with developmental problems forms the basis of periodic reporting and can inform future health program planning.³⁷ In summary, the health approach, concepts, infrastructure, and resources marshaled in

What this paper adds

- International health-program survivors have significant developmental delays and disabilities.
- Early diagnosis and intervention programs are essential to ameliorate developmental delays and disabilities, and are feasible in developing countries.organizations.

some high-income countries have already provided models that can be adapted and partially replicated in resource-poor areas.

CURRENT PRACTICE OF EARLY DETECTION AND INTERVENTION

Most teaching programs in LMICs still concentrate on 'growth' aspects of pediatrics alone. Health staff are trained primarily in the treatment of acute childhood illnesses. Often they have limited sensitization, interest, or training in child development or recognition of early neurodevelopmental delays.³⁸ This is understandable given the emphasis on improving survival, but it is no longer acceptable. Studies of recent medical school graduates in Malaysia, for example, indicate a paucity of clinical exposure and training in identifying and caring for children with developmental disabilities.³⁹ In this setting parents often have strong cultural values and myths about child development and healthcare. They might be unaware of the significance of serious developmental delays or the presence of significant neurodevelopmental disorders.^{40–42} Usually medical attention is sought because of acute illness rather than developmental or behavioral concerns. Combined with the practitioners' frequent lack of developmental awareness, delays and even specific developmental deficits might be completely overlooked as the child is treated for an unrelated acute illness.

It is likely that there are multiple factors that influence the acceptance and practice of early detection and intervention, although data are limited. These include physician attitudes, awareness, or interest;⁴³ insufficient training;⁴⁴ doubt about the value of early detection or non-acceptance of early treatment;⁴⁵ uncertainty about how or where to refer;⁴⁶ time limitations of the clinic visit and inadequate reimbursement;⁴⁷ and cost factors.⁴⁸ In some cases practitioners might be legitimately concerned about unnecessarily alerting a family and would prefer to wait until the problem is too obvious to ignore.⁴⁹ The appropriate education and training, issues affecting professional interest, motivation, and health-provider acceptance, need extensive study in the context of local geographic and cultural conditions.

Intertwined in the spectrum of responses of healthcare practitioners are a variety of approaches and instruments used in the practice of early diagnosis. In high-income countries there is an ever-growing trend to rely heavily on the use of screening instruments by practitioners. Among the many developmental/behavioral screening tools in use in the USA, for example, are the Ages and Stages Questionnaire,⁵⁰ Parents' Evaluation of Developmental Status,⁵¹ and the Denver Development Screening Test II.⁵² More specific screening and/or diagnostic evaluation tools include the Connors ADHD Rating Scales,⁵³ Modified Checklist for Autism in Toddlers,⁵⁴ Autism Diagnostic Observation

Schedule,⁵⁵ and the Autism Spectrum Screening Questionnaire.⁵⁶

Screening tools for use in LMICs are also now emerging, although there are limited reliable data about availability of effective services.⁵⁷ Examples include using caregiver developmental reports in Kenya,⁵⁸ the Malawi Developmental Assessment Tool,⁵⁹ the Rapid Neurodevelopment Assessment Instrument in Bangladesh,⁶⁰ and the Brigance developmental screening tool for aboriginal children in Australia.⁶¹ Screening instruments, however, are often difficult and expensive to administer in the course of routine care,⁶² and might have inadequate sensitivity,⁶³ cultural relevance,⁶⁴ and variable predictive validity.⁶⁵ In practice, screening is often sporadic, infrequent, or non-existent. Moreover, screening tools cannot substitute for good practice in routine primary care, which ideally includes an appropriate history, clinical examination, and relevant laboratory studies as available.⁶⁶

Although the complex issues affecting formal screening need definitive research, regular surveillance of development during clinical contacts offers an easily administered means of early detection with minimum cost, yet enables referral for further evaluation and intervention where appropriate. This approach could be easily incorporated into routine training at all levels and promote an awareness that medical care involves going beyond reducing morbidity and mortality, to planning for the habilitation, education, and social needs of survivors.

FEASIBILITY OF EARLY DETECTION AND INTERVENTION IN LMIC

In LMICs the usefulness of early detection and intervention has been articulated over a long period.⁶⁷ Yet even now, when there are rapidly increasing numbers of child survivors with delays and disabilities, early identification is often not well appreciated, and its implementation has become a central challenge. We propose that there are feasible strategies available for rigorous testing, which, if proven effective, could be made widely available to reach as many children as possible. One such strategy is to use a surveillance approach in primary pediatric healthcare for routine observation of early childhood milestones. Longitudinal progress in milestones has been shown to be a significant predictor of developmental outcome.⁶⁸ Assessing achievement of milestones can enable rapid distinction between simple delay in the pace of development and a non-progressive disability, such as intellectual deficit, cerebral palsy, or a progressive neurological disorder. Indication of definite milestone delays could then lead to formal screening, including taking a relevant history, performing clinical evaluation, and using laboratory studies, depending on available local resources. Unfortunately, there are currently no data available from community-based rehabilitation or other programs on the regular use of culturally relevant childhood developmental milestones in routine surveillance in LMICs.⁵⁷ Such a procedure could be readily incorporated into training programs with minimum additional time requirements or expense for administration. By analogy, growth charts (i.e.

height and weight) have been in routine use over a long period with a similar purpose, and few would question their usefulness. Thus, we can be optimistic that developmental milestones can also be effectively monitored in routine care.

A surveillance instrument of this type was used in a trial in Cambodia to alert, remind, and sensitize health workers of relevant developmental milestones using a simple check-off sheet grouped by age intervals.⁶⁹ Possible future refinement of the Cambodia milestones selected would be based on recent doctoral work.⁷⁰ Emphasis here is on developmental surveillance, which is routine, quick surveillance of 'well' children at specific ages at the primary healthcare level, versus formal screening by medical professionals. Levels accomplished would be noted as either observed by the health worker or obtained from caregiver interview, and could serve as the basis for possible further evaluation. An equivalent developmental milestone surveillance tool is now being incorporated into the South African Road To Health Booklet, which is distributed to the mothers of all newborn infants and checked at well-baby visits.⁷¹ Further local adaptation will follow, bearing in mind the cultural context and different levels of health services, ranging from community to tertiary.

Information on medical and healthcare models for LMICs is limited in all available databases, and programs vary greatly.⁵⁷ Yet data indicate that early identification can be a feasible and effective component to support children and their families, even where specialized treatment services or equipment are not readily available. For example, early detection creates opportunities for parent education and support, which has been shown to have a great influence on parent-child interaction.⁷² It can enhance home management through parent training in more appropriate daily child care, such as carrying, holding, feeding, dressing, and bathing.⁷³ Where early intervention services are available, as in community-based rehabilitation⁷⁴ and other documented programs,^{75,76} it can result in specific motor, speech, or other therapies, and the use of specialized feeding and motor equipment. Such interventions can improve quality of life and enhance future cognitive, motor, and social development for a child with neurodevelopmental delay or disability.^{77,78} Data show that the procedures of early intervention stimulation, specialized therapy care, and the use of appropriate equipment are significant factors in helping achieve maximum benefit to the growing child.^{79,80} They can provide significant support to families,⁸¹ and can be effectively incorporated into childhood developmental programs.⁸² Further research is needed to validate effectiveness of these procedures in a global context.

Clearly, it would not be appropriate to propose the same procedures that are used in high-income countries. We suggest, however, that this challenge can be met. We can develop ways to introduce early detection into routine pediatric care in LMICs, as well as to introduce effective interventions that can follow.

BARRIERS IN GOVERNMENTS AND OTHER AGENCIES

There is a wide gap between international health-program awareness and planning for early diagnosis and intervention in

light of the increasing numbers of surviving children with delays and developmental deficits. The international health programs of the US Agency for International Development (USAID) have extensive activities throughout the developing world. Like other individual government efforts, the focus is primarily on improving nutrition and reducing infectious disease. There is sparse mention of development concerns about young surviving children or, specifically, early screening or intervention.⁸³

The World Health Organization (WHO) and the United Nations Children's Fund (UNICEF) jointly participate in the Integrated Management of Childhood Illness (IMCI) program, working to improve health-worker knowledge and performance through training. Since 2001 there has been an emphasis on development of child survivors. However, the focus in its chart booklet for clinical case management has been confined to treatment of acute illness and after-care only of sick children.^{84,85} The WHO's Care for Development counseling materials, which form part of the IMCI strategy, use counseling to promote healthy development of children. This is intended to offer a feasible community-level strategy in low-resource settings. The Care for Development approach is a way to sensitize communities and individual caregivers to child development issues. The Pan American Health Organization introduced the 'Monitoring Child Development in the IMCI Context' manual in 2005 to achieve awareness of development and to enhance developmental surveillance at primary health level, but widespread acceptance of the early identification approach remains lacking. Indeed, even within the United Nations itself, where 193 members adopted the Millennium Development Goals in 2000 to reduce the under-5 mortality between 1990 and 2015 by two-thirds, there is no mention of planning for early involvement with childhood survivors in its Goal 4 (Child Health).⁵

Similarly, the large non-governmental organizations such as the Bill and Melinda Gates Foundation, the William J. Clinton Foundation, and the Carter Center,⁸⁶⁻⁸⁸ focus on disease eradication along with broad development activities, but do not target identifying early and providing developmental care for the child survivors with delays or deficits. We are led to conclude that among the world's health leadership within governments, official international agencies, and non-governmental organizations, the focus of activity concerns mortality reduction without significant attention to or planning for early identification of surviving children, or providing for the proven interventions most likely to help achieve their optimum capability.

THE PATH FORWARD

A global strategy is needed to narrow the gap between early identification and the increasing population of children with delays and disabilities. This can best be achieved through acceptance of five basic principles.

First, it is essential that there is a broad understanding and awareness of trans-cultural child development. This

sensitization then should lead to the routine practice of thinking developmentally wherever healthcare is given, even while attention is focused on specific disease entities or acute medical problems. Where there is any question of possible developmental delay or disability, early referral should be considered for further evaluation and intervention consistent with avoiding excessive false-positive results. It is recognized, however, that even children showing false-positive results might constitute an at-risk group justifying additional evaluation.⁸⁹ To think developmentally and refer early (TDRE) should be an integral part of all clinical contact and planning, and routinely included in all health staff training. This concept should be subject to rigorous research in cultural context.

Second, health care must be recognized as a concept involving ongoing child development and not be restricted to reduction in morbidity or mortality. This should lead to broad planning for the social and educational needs of survivors.

Third, in LMICs there is need for simple culturally relevant surveillance systems to alert and remind practitioners about development in all health contacts, and enable early referrals.

Fourth, in high-income countries, research is still needed to improve education and training programs as well as to identify factors that will affect motivation and acceptance of early identification by all practitioners.

Fifth, broad community planning and involvement is essential to enable understanding and acceptance of health and development goals. In LMICs, in particular, an approach is needed that will ensure local capacity building for the future to enable the broadest juxtaposition of health, education, and social objectives. Specific programs of early childhood education need to emerge, both for children with delays and disabilities and those with normal development.

Some of these principles can be incorporated immediately. Others will require new approaches to research for future implementation. Many will necessitate changes in understanding, attitudes, concepts, and even financial considerations. There is now ample evidence that, ultimately, we must be guided along the lines of the above principles, without which the very children whose lives we save might achieve little of the promise of the future.

CONCLUSION

It is becoming increasingly essential to influence health agencies and practitioners to go beyond simply reducing morbidity and mortality, and instead to emphasize quality of life as a major health goal now. Early evaluation and intervention includes not only management and treatment for the individual child, but also provision of appropriate family and community-based support mechanisms. It is but a first step on the long road to ensuring the needed services that will enable every child to reach their best potential and to assume a productive role in society.

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