

**CDC/ICDL COLLABORATION REPORT ON A FRAMEWORK FOR
EARLY IDENTIFICATION AND PREVENTIVE INTERVENTION OF
EMOTIONAL AND DEVELOPMENTAL CHALLENGES**

**Centers for Disease Control and Prevention (CDC) and the
Interdisciplinary Council on Developmental and Learning Disorders (ICDL)
Work Group on Early Identification and Preventive Intervention:**

José Cordero, M.D., M.P.H., Stanley I. Greenspan, M.D., Margaret L. Bauman, M.D., T. Berry Brazelton, M.D.,
Geraldine Dawson, Ph.D., Barbara Dunbar, Ph.D., Peter C. Mundy, Ph.D., Ruth Perou, Ph.D.,
Keith G. Scott, Ph.D., Stuart G. Shanker, D.Phil., and Ruth E. K. Stein, M.D.

November 11, 2006

This report is available for downloading from: www.icdl.com or www.cdc.gov/ncbddd/dd/

Hard copies available from:

The Interdisciplinary Council on Developmental and Learning Disorders (ICDL)
4938 Hampden Lane, Suite 800, Bethesda, Maryland 20814 – 301-656-2667

or

The Centers for Disease Control and Prevention (CDC)
1600 Clifton Road, N.E.
Atlanta, GA 30333 USA

Tel: (404) 639-3311 / (800) 311-3435

CDC/ICDL Workgroup on Early Identification and Preventive Intervention

José Cordero, M.D., M.P.H. (co-chair)

Director, National Center on Birth Defects and
Developmental Disabilities

Centers for Disease Control and Prevention

As of November 2006:

Dean, School of Public Health

Medical Sciences Campus

University of Puerto Rico

Stanley I. Greenspan, M.D. (co-chair)

Clinical Professor of Psychiatry and Pediatrics

George Washington University Medical School

Chair, Interdisciplinary Council on Developmental and
Learning Disorders

Margaret L. Bauman, M.D.

Medical Director,

Learning And Developmental Disabilities Evaluation and
Rehabilitation Services (LADDERS)

Massachusetts General Hospital

T. Berry Brazelton, M.D.

Professor of Pediatrics Emeritus

Harvard Medical School

Founder, Brazelton Touchpoint Center

Geraldine Dawson, Ph.D.

Professor of Psychology

Adjunct Professor of Psychiatry and Behavioral Sciences

Director, University of Washington Autism Center

University of Washington

Barbara Dunbar, Ph.D.

Developmental Psychologist

Adjunct Professor, Georgia State University

Peter C. Mundy, Ph.D.

Professor, Psychology and Pediatrics

Executive Director, Center for Autism and Related
Disabilities

University of Miami

Ruth Perou, Ph.D.

Child Development Studies Team Leader

National Center on Birth Defects and Developmental
Disabilities

Centers for Disease Control and Prevention

Keith G. Scott, Ph.D.

Professor of Psychology and Pediatrics

University of Miami

Stuart G. Shanker, D.Phil.

Distinguished Research Professor of Philosophy and
Psychology

Director, The Milton and Ethel Harris Research Initiative
York University

Toronto, Ontario

Ruth E. K. Stein, M.D.

Professor, Department of Pediatrics

Albert Einstein College of Medicine

Children's Hospital at Montefiore

CDC/ICDL COLLABORATION REPORT ON A FRAMEWORK FOR EARLY IDENTIFICATION AND PREVENTIVE INTERVENTION OF EMOTIONAL AND DEVELOPMENTAL CHALLENGES

José Cordero, M.D., M.P.H., Stanley I. Greenspan, M.D., Margaret L. Bauman, M.D., T. Berry Brazelton, M.D., Geraldine Dawson, Ph.D., Barbara Dunbar, Ph.D., Peter C. Mundy, Ph.D., Ruth Perou, Ph.D., Keith G. Scott, Ph.D., Stuart G. Shanker, D.Phil., and Ruth E. K. Stein, M.D.

INTRODUCTION

Reports of increasing rates of autistic spectrum disorders (ASDs), as well as other mental health disorders such as attention-deficit/hyperactivity disorder (ADHD), obsessive compulsive disorders (OCD), Tourette's Syndrome, have spurred a growing interest in early identification and early preventively-oriented interventions for developmental and emotional challenges in infancy and early childhood. There are, however, a wide range of developmental challenges that require early identification and preventive intervention. In the United States, approximately 17% of children have a developmental or behavioral disability such as autism, mental retardation, and ADHD. In addition, many children have functional challenges in communication, cognitive abilities, and behavioral regulation that do not meet the criteria for a specific disorder, as well as delays in other areas that also impact school readiness (U.S. Department of Education, 2000).

However, less than 50% of these children are identified as having a problem before starting school, by which time significant delays may have already occurred and opportunities for healthy development have been missed. The public health challenge is formidable, as we often identify children with delays and challenges after the optimal time for prevention and/or early intervention. Even when we do identify children with challenges early in their lives, our early intervention programs are either unavailable where needed or insufficient in their intensity and comprehensiveness. The argument for a change in our policy towards children and families, in terms of productive lives lost, economic opportunities missed and the cost to society have been made by many groups. These arguments become particularly compelling when we see that growing knowledge is providing the basis to meet these challenges.

For example, both research and clinical practice suggest that following essential developmental processes are vital for healthy functioning and are often impaired in various types of challenges. These processes are often described in different ways by clinicians and researchers. They include compromises in the range, stability, and flexibility of the capacities for:

- Self-regulation and attention
- Relationships (attachments)
- Social interactions, i.e., reciprocity and increasing social problem-solving (including multiple joint attentional frames and initiating reading and responding to intentions)
- Meaningful use of language (pragmatic) and play (with toys or other objects), as well as the meaningful use of ideas (symbols) coupled with the progression to logical and abstract thinking.

Yet, there are questions that need to be raised as enthusiasm for earlier and earlier identification and intervention mount. If, for example, the approaches to early identification or intervention are too narrow or are based primarily on pathological functioning rather than healthy adaptive functioning, even the best-intended efforts could have negative consequences. Therefore, it is essential to formulate broad parameters that can guide current efforts to improve our ability to identify infants, young children, and families at risk and organize truly comprehensive, developmentally-based intervention efforts. While a number of these parameters are part of efforts such as the Bright Futures program and those of the American Academy of Pediatrics, it may prove helpful to systematize them. Principles that may usefully be considered include the following:

A Developmental, Adaptational Framework

The primary goal of caregiving early in life (and throughout our lifespan) is to facilitate healthy functioning. For infants and young children at risk for developmental problems, this goal is essential. However, it requires having a roadmap of what constitutes healthy functioning, including healthy intellectual, language, emotional and social, sensory, and motor capacities, as well as family functioning. Such a roadmap, for example, can help parents and professionals understand why a child, who can label objects, knows numbers and letters, and may even be reading, may nevertheless have significant language or emotional challenges (e.g., in the social or pragmatic use of language) or why a child is verbal and intelligent may have challenges with both family and peer relationships. In addition, approaches that focus solely on reversing a particular pathological symptom or altering isolated behaviors may miss the opportunity to facilitate more generalized healthy functioning and, in certain instances, by concentrating on a few behaviors, may even undermine it. Therefore, it is critical for both early identification and preventive intervention efforts to embrace a model of healthy functioning as an overall framework. In such a model, efforts to reverse or ameliorate pathologic elements would always be implemented as part of a comprehensive program that facilitates healthy development in all areas of functioning.

A Comprehensive Approach

Healthy development involves many areas of functioning, including intellectual and cognitive functioning, language functioning, social and emotional capacities, sensory and motor abilities, and environmental patterns. To promote healthy functioning, early identification and preventive intervention efforts must deal with all these areas of functioning in an integrated manner (including understanding relationships between them) (Greenspan & Shanker, 2004).

A Functional Perspective

The history of attempts to understand developmental disorders, as well as other health, mental health, or developmental challenges, has been characterized both by searching for discrete pathological processes that would identify well-defined disease entities, as well as detailed descriptions of functioning (functional capacities). One cannot stress enough the importance of functional approach. Such an approach is essential for early identification and preventive intervention efforts.

While many features of developmental problems support the need for a functional approach, a particularly compelling argument can be found in the following fact—most emotional and developmental problems and disorders embody a wide range of variation in functioning. For example, some children with conduct disorders may be active sensory craving coupled with family patterns where empathy and limit-setting are compromised, while others with similar behavior may be unable to develop trusting relationships and compassion due to emotional deprivation. Similarly, children with ADHD or attentional problems may have significant challenges in their ability to carry out actions that involve multiple steps (planning and sequencing) and/or have significant challenges with language or organizing what they see (visual-spatial processing). Children with ASD vary considerably, including differences the way they react to touch and sound, remember what they see or hear, and plan their actions.

It is quite likely that we will discover different developmental pathways and different underlying biological patterns for these functional differences. In the meantime, however, it is essential to capture these functional differences in our identification and intervention programs. Without understanding these differences (each child's unique profile), it is impossible to construct an approach that will truly be helpful for the child and her family.

Even children with disorders with well-described pathophysiological processes, such as Fetal Alcohol Syndrome, Fragile X Syndrome, and Down Syndrome, vary enormously in their functional capacities. Children with these diagnoses may show a range of language, visuospatial, motor planning, sensory modulation, and social and emotional functioning (e.g., from circumscribed learning challenges to major cognitive and social deficits). Children from multi-risk families and environments also show a range of functioning, depending on a complex array of biological, psychological, and social factors.

A functional approach is particularly challenging because all children, both with and without problems, evidence enormous variation in their development trajectory. As a consequence, it is often important to see a child and his or her family a number of times to observe the scope of the child and family's functioning. Even more important, a single observation can misleadingly overemphasize a specific problem without observing either the child's strengths or perhaps other challenges. Equally important, however, the human brain and mind demonstrates enormous plasticity. Both animal and human studies are emphasizing the degree to which favorable experiences can lead to positive mental growth associated with favorable changes in brain functioning. In order to create such favorable experiences for children at risk or who are already evidencing developmental challenges; however, it is essential to have an understanding of their functional capacities.

A functional approach also enables caregivers, as well as members of the intervention team, to understand and tailor interventions to each child as a unique human being with different strengths, weaknesses, relationships, and family patterns.

Family and Environment

A large number of different family patterns and environments play an important role in children's developmental patterns. Early in life, for example, chaotic or depriving caregiving can severely disrupt many areas of mental functioning, including language, social and emotional capacities, and the ability to process information and learn. Mounting evidence suggests that these environmental patterns affect not only the child's mind, but the structure of his or her central nervous system. By the same token, favorable and enriched experiences tailored to the individual needs of the child and his or her family can exert very positive developmental influences (Shonkoff & Phillips, 2000).

Therefore, family and environmental patterns are important components of early identification and preventive intervention efforts. Understanding these patterns is essential for appreciating the nature of the developmental risk, the mechanism through which it is occurring, and the type of program that will be required to work with it.

Clinical experience and research also suggests that attempts at early identification of challenges with at-risk families requires ongoing trusting relationships and an understanding of the beliefs, values, and coping strategies of caregivers (e.g., for obtaining reliable information about a child's development). Asking a parent about an area of the child's functioning that is very important to the parent will often lead to a rich description, in comparison to a question about whether the child has this or that problem.

Yet, creating relationships that will facilitate communication and understanding and lead to the reliable identification of challenges in at-risk groups is very difficult to do with large numbers of children and families, especially with multi-problem families. Furthermore, multi-problem families often evidence multi-generational patterns of marginal functioning characterized by learning problems, delinquency, criminal activity, and mental health disorders (Buell, 1952; Greenspan, et al., 1987). A number of mental health disorders that can interfere with caregiving, such as maternal depression, can be present in any family.

Organizing Developmental Processes

Modern research has identified a number of critical developmental processes that are important for multiple areas of functioning, including intellectual, language, social and emotional, and learning capacities. Examples include state regulation (Brazelton & Nugent, 1995), attachment (Ainsworth, Bell, & Stayton, 1974; Bowlby, 1969, 1973), sensitivity to emotional cues and social reciprocity (Dawson, et al., 2004), joint attention (Mundy & Sigman, 2006), imitation, emotional discrimination and interaction (Sigman et al., 2004). Individual investigators have demonstrated associations between these core developmental processes and a number of later social and intellectual capacities. For example, Mundy and Sigman (2006) have shown that joint attention is associated with a number of later social and cognitive capacities; Dawson (Dawson, et al., 2004) has shown that problems in social reciprocity are associated with later language and social capacities; Brazelton has demonstrated that self regulation facilitates early relationships and development (Brazelton & Nugent, 1995); and Ainsworth, Sroufe, and

Main (Ainsworth, 1982; Carlson, Sampson, & Sroufe, 2003; Main, 1996), have demonstrated that early attachments are associated with later emotional and coping capacities.

Recently, Greenspan and Shanker formulated a number of foundational developmental processes (Greenspan & Shanker, 2004) and in a study on over 1500 families showed that these developmental processes in the first year of life predicted symbolic and language functioning in early childhood (Greenspan & Shanker, 2006-in press). Moreover, straightforward functional questions about these processes were added to the National Health Survey used by the National Center Health Statistics (the HHS) on over 15,000 families and were found to be easily understandable and to identify 30% more families with evidence of developmental challenges than standard questions about the presence or absence of developmental difficulties (Simpson, Colpe, & Greenspan, 2003).

These include the capacity for self-regulation and attention, the capacity for relationships (attachments), the capacity for social reciprocity and increasing social problem-solving (including multiple joint attentional frames and initiating reading and responding to intentions), the capacity for pragmatic language, the meaningful use of symbols or ideas and logical and abstract thinking.

As indicated earlier, these essential developmental processes are vital for healthy functioning and are often impaired in various types of challenges. Early identification and preventive intervention efforts guided by these essential developmental processes will facilitate the identification of infants and children at risk who currently “slip under the radar.” For example, many children later diagnosed with attentional problems evidence early difficulties with carrying out multiple-step actions (planning and sequencing) or lots of over- or underreactivity to basic sensations, such as sound and touch. Children with global developmental delays often evidence early difficulties in social reciprocity and joint attention (social problem-solving). Children later identified as evidencing ASD often have early difficulties with initiating, reading, and responding to the intentions of others which may be obscured by relatively strong memory capacities. Many standardized assessment tools rely heavily on rote memory and motor capacities and, therefore, may contribute to overlooking infants and children who would benefit from early intervention. Most importantly, because these core developmental processes influence multiple areas of functioning, including language, cognitive, emotional and social functioning, and involve relationships with key caregivers, they are a vital foci for a comprehensive early intervention program. It is also important to emphasize that while there has been a great deal of research on these core developmental processes in children with some diagnoses, such as ASD, there are also challenges in the mastery of these very same processes with children who evidence a large range of developmental challenges (e.g., Down Syndrome, Fragile X Syndrome, Fetal Alcohol Syndrome, environment neglect or abuse, etc.).

These essential developmental processes can be easily observed or elicited with very straightforward questions. At a time when “medical homes” are more at risk, when our dominance by insurance companies and HMO’s force us to practice a less satisfying health care it is a time to consider the mandate that parents are the experts on their child’s behavior, and we would be wise to “listen” rather than “tell.” Nearly all parents of delayed children have already

recognized their child's delays and disorganization by the time they seek our advice. Reassurances are not enough and are likely to be met with anger and the feeling from parents that we "just don't care enough to be involved!" Instead, when we cannot be sure, we can listen and try to join parents in facing with them their questions and in their anxieties. Even to seek help from other professionals who can spend the time and have the expertise to identify delays as early as possible. For we are all aware now that early intervention, appropriate to the child's delay, can make a significant difference in the child's ultimate development. Identification of the reasons for the delays comforts parents and helps to prepare them for their work toward intervention and helping to reorganize a disordered child.

Below are examples of questions that can be asked of parents for each core developmental process to elicit a dialogue.¹ These types of questions may help monitor development and identify the children who would benefit from formal screening and comprehensive evaluations.

- **Self-regulation and attention** (first 3 months and thereafter)
 - ❑ How do you feel about the way your baby looks at you?
 - ❑ Does your baby look toward you when you are talking?
 - ❑ Does your baby look toward you when you are smiling or giving him other interesting looks?
 - ❑ How do you feel about the way you are able to help your baby calm down?
 - ❑ Are you able to calm your baby?

- **Relationships (attachments)** (3 to 5 months and thereafter)
 - ❑ How do you feel about your relationship with your baby?
 - ❑ Is your baby usually happy and smiling and making interesting sounds when he or she sees you?

- **Social interactions, i.e., reciprocity and increasing social problem-solving (including multiple joint attentional frames, initiating reading and responding to intentions, and social referencing)** (8 to 18 months and thereafter)
 - ❑ How do you feel about the way your baby or toddler interacts with you?
 - ❑ Does your baby initiate interactions with sounds or smiles and then respond with more sounds or smiles after you respond?
 - ❑ Does your baby look at you for decisions?
 - ❑ Does your toddler (12-18 months) show you what he or she wants and try to get your help to get what he or she wants; for example, taking you to the refrigerator for juice or to where his toys are to find a favorite toy?
 - ❑ Does your toddler take delight in showing you a toy or a favorite picture in a book?
 - ❑ Does your toddler come to you for support?

¹ These questions are based on two studies involving large representative populations that demonstrated that these types of questions could discriminate children with no challenges from children with developmental challenges, predict later functioning, and identify 30% more children with challenges than questions which were only asked if there was a problem or a disorder (Simpson, Colpe, & Greenspan, 2003).

- **Meaningful use of language (pragmatic) and play (with toys or other objects), as well as the meaningful use of ideas (symbols) coupled with the progression to logical and abstract thinking (18 to 48 months and thereafter)**
 - How do you feel about the way your toddler or preschooler uses words or ideas?
 - Does your toddler use words to let you know what he wants or what he is feeling?
 - Does your toddler engage in pretend play (feeding a doll or having a doll ride in a car)?
 - Does your toddler interact with other children his age?
 - Does your preschooler (30 to 48 months) use a number of ideas in a row in a way that makes sense to you, e.g., “The baby doll is hungry. I’m feeding it.”
 - Does your preschooler tend to answer your questions, such as “Where is the truck going?” “Over there.” Why do you want to go outside “Because I want to play”

CONCLUSION

The principles outlined above need to inform our early identification, assessment, and preventive intervention efforts. Clearly, the parameters of functioning embodied in these principles need to be approached at varying levels of detail and depth, depending on the specific goal. Screening efforts will need to touch on these factors; a full evaluation will need to go into a reasonable degree of depth and detail; a comprehensive preventive intervention program will require not only detail and depth, but continuing work on these areas of functioning.

It may appear to be a tall order for programs to embody all these principles. However, insufficient attention to each of these will result in either missing an opportunity to be helpful to infants, children, and families at risk, intervention programs which do not sufficiently focus on the healthy foundations of development and, therefore, are not as helpful as they can be, or programs that actually undermine healthy functioning by focusing the family’s and the therapeutic teams’ energies on mistaken goals.

Therefore, it is essential to be guided by developmental principles and goals. Only a broad comprehensive functional developmental approach will enable professionals and parents to understand the children they are working with and to put into proper context existing screening tools, assessment procedures, and intervention strategies.

In summary, early identification and preventive intervention is receiving greater and greater public attention. The growing knowledge of how the mind and brain develops offers promise for future generations. However, efforts must be guided by an appreciation of the full complexity of human development and the dynamic processes and broad bio-psychosocial context within which it occurs.

REFERENCES

- Ainsworth, M. D. S. (1982). Early caregiving and later patterns of attachment. In: M. H. Klaus & M. O. Robertson (Eds.), *Birth, interaction, and attachment*. Pediatric Round Table, No. 6, Johnson & Johnson, pp. 35-43.
- Ainsworth, M., Bell, S. M., & Stayton, D. (1974). Infant-mother attachment and social development: Socialization as a product of reciprocal responsiveness to signals. In M. Richards (Ed.), *The Integration of the Child into a Social World* (pp. 99-135). Cambridge, England: Cambridge University Press.
- Bowlby, J. (1969). *Attachment and loss*. (vols. Vol. 1) London: Hogarth Press.
- Bowlby, J. (1973). *Attachment and loss*. (vols. Vol. 2) New York: Basic Books.
- Brazelton, T.B., & Nugent, J.K. (1995). *The Neonatal Behavioral Assessment Scale*. Mac Keith Press, Cambridge.
- Carlson, E., Sampson, M., & Sroufe, L. A. (2003). Attachment theory and pediatric practice. *Journal of Developmental and Behavioral Pediatrics*, 24 (5), 364-379.
- Dawson, G., Toth, K., Abbott, R., Osterling, J., Munson, J., Estes, A. & Liaw J. (2004). Defining the early social attention impairments in autism: Social orienting, joint attention, and responses to emotions. *Develop. Psychology*, 40(2), 271-283.
- Greenspan, S. I., & Shanker, S. (2004). *The first idea: How symbols, language and intelligence evolved from our primate ancestors to modern humans*. Boston: Da Capo Press, Perseus Books.
- Greenspan, S. I., & Shanker, S. (2006). The developmental pathways leading to pattern-recognition, joint attention, language and cognition.
- Greenspan, S.I., Weider, S., Lieberman, A., Nover, R., Lourie, R., and Robinson, M. *Infants in multirisk families: Case studies in preventive intervention*. Clinical Infant Reports, No. 3. New York: International Universities Press, 1987.
- Main, M. (1996). Introduction to the special section on attachment and psychopathology: 2. Overview of the field of attachment. *J Consult Clin Psychol*, 64(2): 237-243.
- Mundy, P. & Sigman, M. (2006). Joint attention, social competence and developmental psychopathology. In D. Cicchetti and D. Cohen (Eds.), *Developmental Psychopathology, Second Edition, Volume One: Theory and Methods*, Hoboken, N.J.: Wiley.
- Shonkoff, J. P. & Phillips, D. A. (2000). *From Neurons to Neighborhoods: The Science of Early Childhood Development*. National Research Council, Committee on Integrating the Science of Early Childhood Development.
- Sigman, M., Angeline, D., Gratier, M., & Rozga, A. (2004). Early detection of core deficits in autism. *Mental Retardation and Developmental Disabilities*, 10, 221-233.
- Simpson, G. A., Colpe, L., & Greenspan, S. I. (2003). Measuring functional developmental delay in infants and young children: Prevalence rates from the NHIS-D. *Paediatric & Perinatal Epidemiology*, 17, 68-80.
- U. S. Department of Education (2000). *Twenty-second annual report to Congress on the implementation of the Individuals with Disabilities Education Act*. U. S. Department of Education: Washington, DC.