

Part One:

Overview and Recommendations

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Introduction

***Stanley I. Greenspan, M.D., Chairman
Interdisciplinary Council on Developmental and Learning Disorders***

Increasing numbers of young children are presenting with non-progressive developmental disorders involving compromises in the capacities of relating, communicating, and thinking. These developmental disorders include autistic spectrum disorders, multisystem developmental disorders, cognitive deficits, severe language problems, types of cerebral palsy, and others. They involve many different areas of developmental functioning, ranging from planning motor actions and comprehending sounds to generating ideas and reflecting on feelings. New research and clinical observations are making it possible to more fully identify these different capacities and, thereby, characterize each child and family according to their unique profile of functional developmental capacities. These new observations also make it possible to subdivide complex developmental disorders, such as autism, based on different configurations of functional or dimensional processes (e.g., auditory processing, motor planning, and reciprocal, affective interactions). Most important, they enable clinicians to individualize assessment and intervention approaches in response to the child-and-family-specific question: “What is the best approach for a given child and family?” Answering the child-and-family-specific question makes it possible for clinicians to tailor the approach

to the child, rather than fit the child to the program.

Too often, however, the clinical practice is to fit the child to a standard program. The rationale for fitting the child to the program is, in part, driven by theory and belief (e.g., all children with autism should receive a specific approach, regardless of their individual developmental profiles). It is also driven by the mistaken assumption that children who share a diagnosis because they display some similar symptoms also have a similar central nervous system processing profile and underlying neurobiology.

There are, however, different neurobiological patterns, in addition to different functional developmental or dimensional processes, within each broad diagnostic group, such as autism. These findings make it timely and imperative to formulate clinical practice guidelines that go beyond traditional diagnostic categories and are based on functional developmental or dimensional differences.

Over the years, the disciplines that work with developmental disorders have constructed a large body of research and clinical experience based on these functional developmental or dimensional processes. This knowledge, however, needed to be brought together and organized. In response to this need, the Interdisciplinary Council on Developmental and Learning

Disorders (ICDL) launched an initiative to systematize the current clinical knowledge, including both research and clinical experience, of disciplines such as speech pathology, developmental and behavioral pediatrics, pediatric neurology, occupational and physical therapy, psychology, social work, special education, early childhood education, early intervention, and child psychiatry. The result of this effort is *The ICDL Clinical Practice Guidelines*.

The ICDL Clinical Practice Guidelines is unique in three ways. First, the guidelines go beyond syndrome-based approaches and build on emerging knowledge of different functional developmental patterns within broad syndromes, such as autism. This specificity enables the identification of each child and family's unique developmental profile, including strengths and vulnerabilities, and the development of an individualized intervention plan that works with all the relevant functional developmental and processing capacities.

Second, *The ICDL Clinical Practice Guidelines* addresses a level of clinical complexity, detail, and depth not often attempted with such efforts. The guidelines recognize the need to go further than simply documenting, in broad strokes, the value of interventions such as special education, social skills training, and/or communication and speech and language therapy. The guidelines recognize that there is enormous variation in clinical goals, techniques, and therapist/child interactions within similarly named interventions (e.g., speech and language therapy), based on the individual challenges of a particular child and family and on the practitioner's personality, training, skill level, and interactive patterns with a particular child and family. The guidelines, therefore, attempt to describe specific strategies and interaction patterns for the different functional areas: For

example, how to work with a child who is very overreactive to touch, underreactive to sound, has poor motor-planning skills, is very avoidant, and moves away from adults and other children to help him learn to enjoy caregiver and peer relationships, interact, communicate, and problem solve. This type of child-specific clinical work requires enormous clinical skills. These skills, which will often determine the success of the overall intervention program, can only be captured by in-depth clinical descriptions that go significantly beyond the identification of a generic intervention category.

Elaborating upon and systematizing in-depth clinical strategies to guide intervention efforts require a broad knowledge base supported by both research and clinical experience. The third unique feature of *The ICDL Clinical Practice Guidelines* is that the guidelines are based on both current research and clinical experience (i.e., expert opinion) from all the disciplines that work with developmental problems. A number of organizations have issued, or are issuing, guidelines based predominantly on reviews of current research (or evidence). Although increasing research is an important long-term goal, the current research base is too incomplete to fully guide clinical decisions. It lacks the scope and specificity necessary to guide interventions tailored to the individual child and family's unique developmental profile. (See Tsakiris, Chapter 31, this volume, for a review of current intervention research.) Current research is only able to ascertain, in broad terms, that (1) intervention programs tend to be helpful, (2) intensive and comprehensive programs tend to produce better results, and (3) a few of the related areas of functioning (e.g., language and social skills) have been studied to some degree. There are no comparative clinical trial intervention studies of major intervention models and no

definitive clinical trial intervention studies of comprehensive interventions for representative populations of individuals with autistic spectrum disorders or other disorders of relating and communicating that demonstrate clinically meaningful outcomes. Only selected assessment and intervention procedures have been researched, and many important areas of functioning and related interventions that belong in a comprehensive assessment and treatment program have not been sufficiently studied.

At present and for the foreseeable future, clinical experience together with research is necessary to provide the clinical knowledge needed to individualize approaches to the child and family's functional or dimensional profile. Both are also necessary to work with all the areas of developmental functioning that form the critical foundations for intellectual and emotional growth.

The ICDL Clinical Practice Guidelines addresses the identification, assessment, and treatment of all relevant areas of developmental functioning, including child-caregiver relationships and developmentally appropri-

ate interaction patterns; speech and language, including auditory processing; motor functioning, including planning and sequencing; visual-spatial processing and thinking; other types of sensory processing; and sensory modulation, including patterns of hypo- and hypersensitivity; the functional-emotional developmental capacities of attention and regulation, engagement, purposeful, two-way communication, complex problem solving, the creative use of ideas, and abstract, logical thinking; areas of cognitive functioning; social skills; family patterns; and peer relationships.

The ICDL Clinical Practice Guidelines further addresses how these functional developmental capacities become incorporated into the process of a comprehensive evaluation, the construction of the developmental profile, and the formulation of a child-and-family-specific comprehensive intervention program. The functional developmental approach serves as the basis for recommendations for changes in screening, assessment, and intervention services and local, state, and federal policies. ■

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The Need for a Comprehensive Individualized Approach

As indicated in Chapter 1 of this volume, infants and children with non-progressive developmental and learning disorders evidence challenges as well as strengths in many different areas of functioning. Each of these areas must be worked with as part of a comprehensive assessment and intervention program. Such a comprehensive program involves a number of disciplines working together, guided by the unique developmental profile of the child and the child's family.

Although seemingly self-evident, these basic tenets have been surprisingly difficult to put into practice. For many developmental and learning disorders, disagreement exists about what areas of functioning should be addressed, the best ways to observe and assess them, and the interventions most likely to be helpful. In addition, each child and family is quite unique, and each clinician, regardless of background and training, has a personal way of practicing his or her craft. These challenges are formidable, but dealing with them is necessary to creating an individualized interdisciplinary approach that tailors the program to the child rather than fits the child to the program.

For discussion purposes, non-progressive developmental and learning disorders can be divided into two groups. One group involves disorders that significantly interfere with a child's basic abilities to communicate (preverbally and verbally), to relate to others

in an age-appropriate manner, and to think creatively and logically. A second group involves disorders that are more circumscribed and interfere with different aspects of learning (including regulating activity and attention) but do not significantly interfere with the child's basic ability to communicate, relate, and think. This edition of *The ICDL Clinical Practice Guidelines* will address the first group of disorders, which includes many forms of autistic spectrum disorders (pervasive developmental disorders), multisystem developmental disorders, language disorders, motor disorders, severe cognitive deficits, Down syndrome, fragile X syndrome, fetal alcohol syndrome, severe forms of regulatory disorders and attention deficit disorder, and others. Rather than address each disorder separately, *The ICDL Clinical Practice Guidelines* will focus on the functional developmental deficits, such as speech and language problems, motor-planning dysfunction, affective processing and regulation problems, and sensory processing and modulation difficulties, that are often present in varying degrees across them.

The current state of clinical practice with the non-progressive developmental and learning disorders that interfere with communicating, relating, and thinking is best described by Charles Dickens's often-quoted statement about this being "the best of times, the worst of times." New understandings of central

nervous system mechanisms, processing differences, and innovative practices exist alongside clearly inadequate programs for the majority of children with these disorders.

New understanding of how different behaviors and symptoms are dynamically related to functional developmental and processing differences in many of these disorders (such as autistic spectrum disorders) is providing a basis for improved assessment, diagnostic, and intervention practices. At the same time, neuroscience investigations are revealing dynamic interactions between genetic expression, levels of environmental interaction, and the formation of neurostructures. For example, throughout infancy and childhood, the brain can develop new neuropathways to deal with interruptions, such as a hemispherectomy. Furthermore, individually different, dynamic relationships exist between different areas of the brain. Processing capacities, such as auditory or visual-spatial, may compete for cortical access, depending on functional use. Interactive experience or functional use, including strategically tailored family, education, and therapeutic experiences may, therefore, play a significant role in the development of expectable, new, and alternate pathways (Chugani, 1999; Zimmerman & Gordon, Chapter 27, this volume).

Recent clinical observations and research suggest that there are three interrelated processes that are essential for mobilizing a child's development. The first process is working with each child's individually different underlying processing capacities, such as sensory modulation, auditory and visual-spatial processing, and motor planning. The second process is working with a child's most important functional developmental capacities (the building blocks of intelligence and emotional health), such as shared attention; relating with intimacy; engaging in gestural and affective reciprocal and social interactions; and using

ideas meaningfully, creatively, and logically. The third process involves utilizing new insights into the role of relationships and emotional interactions in facilitating a child's intellectual and emotional growth. For example, the earliest cognitive structures and sense of causality do not, as Piaget believed, first arise from early sensorimotor (cognitive) explorations but from even earlier affective interactions between a baby and his or her caregiver (e.g., a smile begetting a smile). At each stage of early cognitive development, emotional interactions lead the way. The meaning of words, early quantity concepts ("a lot" to a 2¹/₂-year-old is more than he expects; "a little" is less than he wants), logical and abstract thinking, and even important components of grammar depend on specific types of emotional interactions (Greenspan, 1997; Greenspan & Wieder, 1999). These new observations make it possible to construct individualized, affectively based, learning interactions and relationships to promote intellectual and emotional growth. These individualized interventions are based on each child's unique profile of processing differences and functional developmental capacities.

Even though emerging evidence appears to favor this dynamic model, the vast majority of children with major developmental and learning problems have access only to approaches that are based on older, static views. Many of these approaches have not been very helpful and, for the most part, have not changed over many years. These approaches tend to focus on surface behaviors, symptoms, and syndromes and often assume that children having similar symptoms or surface behaviors also have similar underlying processing mechanisms. These approaches do not sufficiently deal with each child's (and family's) unique developmental and processing profile and the child's potential for growth.

Examples of widely used approaches that are not sufficiently based on dynamic developmental

concepts and have not been sufficiently helpful to the majority of children with non-progressive developmental disorders include:

- *Limited educational programs that work with isolated educational skills*, such as matching shapes, without sufficient attention to the developmental stages of pre-verbal relating and communicating and the steps involved in building motor sequencing, visual-spatial processing, auditory and language processing capacities, and imaginative and logical thinking.
- *Behavioral approaches that attempt to be a primary, complete intervention* by working predominantly with surface behaviors and without sufficient attention to critical relating, developmental, and processing capacities.
- *Isolated biomedical approaches* involving various diagnostic procedures and medication without sufficient emphasis on constructing a complementary, comprehensive, functional developmental intervention program. An example is when a diagnostician gives parents their child's diagnosis, offers some recommendations for additional tests and/or a particular medication, and simply tells them to contact representatives of their local special education program (which only offers the limited program just described). Approaches that work intensively and comprehensively with each child's and each family's functional developmental profiles have generally been unavailable.

The challenges many families face in dealing with a service system that lacks the capacity to fully individualize a child's assessment and intervention program is illustrated by the following brief clinical vignette about Roger and his dedicated mother.

“Newly diagnosed with an autistic spectrum disorder, 3-year-old Robert was recommended for speech therapy, a special education program, and a social skills and relationship group. Robert's mother was told that these approaches were often helpful for children with autistic spectrum problems.

On the advice of her pediatrician, Robert's mother looked at a number of speech, special education, and social skills programs to see which would be best for Robert. ‘But they are all so different, even though they are called the same thing,’ she exclaimed. One speech pathologist was very structured, working on repeating sounds and words and labeling pictures. Since Robert was already repeating in a rote manner what he heard on television, his mother worried that this type of therapy might make his speech even more rote. Another speech therapist was very interactive, trying to get Robert to want to communicate with gestures or words, enticing Robert to imitate her when he really wanted something. This type of approach was more appealing to Robert's mother, but she didn't want to be the one who decided. The special education and social skills programs were even more varied in their approaches. Furthermore, none of the programs she observed seemed able to engage children who, like her Robert, always moved away from others. ‘Could they work with a child who was so avoidant?’ she wondered.

The mother also thought Robert might need additional services. He had slightly low muscle tone and had difficulty holding a pencil and copying shapes. He couldn't find his toys or even search for them. Furthermore, he tended to be underreactive to pain, but was overreactive to sound and held his ears whenever there were loud noises. At home, he always walked away from his parents and siblings and isolated himself with aimless wandering or repetitive activities, such as watching a video over and over. After researching these issues,

his mother wondered if Robert also needed occupational therapy and/or work on his visual-spatial processing. What sort of a program should he have for the many hours he spent at home? Without a home program, he would continue to spend most of his time in relative isolation from others. No one had recommended additional approaches or therapies.

Robert's mother recognized that he was unique and not necessarily like other children who shared his diagnosis. She wanted to know what would be best for her son, based on his unique developmental profile. However, she was told that, at present, research could only answer some of her most general questions. It could tell her, for example, that speech therapy, education, and social skills programs were often helpful. It could not tell her what particular principles, or ingredients, or therapists, or educator personality patterns within these approaches would work best for her Robert. Nor could research tell her if he also needed additional programs, or what she and Robert's family should be doing with him at home, to help him learn to engage and become more reciprocal with others and work on motor planning or visual-spatial processing. Seeing how different the similarly named, recommended interventions were and how many unanswered questions she had, Robert's mother, understandably, felt abandoned by the professional community."

To answer this mother's critical questions, it is vital that the service system:

1. Determine the specific clinical principles and ingredients that should guide interventions for complex developmental disorders.
2. Develop methods to determine how to construct an individualized, comprehen-

sive intervention program for a unique child (such as Robert) with his own profile of functional capacities and processing differences.

Meeting these two goals requires an unusually subtle level of clinical detail. It is a level of detail that recognizes:

- *Vital differences in therapies and educational programs that go by the same name*, but which vary widely in practice due to different interpretations of their intervention principles, different practitioner's personal characteristics, and the variety of situations that call for unplanned therapeutic actions that even the most detailed intervention curriculum can't anticipate.
- *Critical differences in the needs and intervention requirements of children* (and families) who may share the same diagnosis, but nonetheless have very different functional developmental capacities (e.g., one child is just learning to engage with others whereas another is working on using words more abstractly) and processing patterns (e.g., one child evidences strong auditory memory and weak visual-spatial processing capacities, whereas another child evidences just the opposite).

The guidelines presented in the chapters that follow systematize clinical knowledge at a level of clinical detail that focuses on individual patterns in an effort to answer the central question about what approach is best for an individual child and family. This is the question posed by Robert's mother and countless other parents as well as by practitioners from all the disciplines that work with non-progressive developmental disorders involving problems in relating, communicating, and thinking. ■

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3**Overview and Recommendations**

Chapters 1 and 2 of this volume describe the clinical observations that suggest that functional developmental, or dimensional, profiles of the child and the child's family should guide the assessment and intervention process for complex, non-progressive developmental disorders. It is apparent that these disorders, which include autism, multisystem developmental disorders, cognitive deficits, and other disorders, involve limitations in a number of areas of functioning, such as language, motor planning (sequencing actions or behaviors), aspects of cognition, and social interaction. At present, research into the underlying etiology of many of these disorders, including autism, has not revealed a single cause or neurological pathway for the variety of these observed deficits in functioning (Bauman, Chapter 29, this volume; Cohen & Volkmar, 1997). In addition, there are no definitive clinical trial studies on comprehensive interventions for representative populations that show a clinically significant change in the course of these disorders, nor are there much-needed clinical trial studies comparing different intensive interventions. (See Tsakiris, Chapter 31, this volume, for a review of intervention research.)

It is also apparent that different disorders can involve similar deficits, and the same disorder can evidence different deficits. Thus, each child, regardless of the disorder diagnosed by symptoms, often evidences his own unique pattern of functional capacities

(Cytryn, 1998; Greenspan & Wieder, 1997, 1998, 1999; Tanguay, Robertson, & Derrick, 1998). Each child, therefore, requires a highly individualized, comprehensive functional developmental approach. (A functional approach is already used in most complex medical disorders, such as heart disease, which also involves multiple causes and physiologic pathways in comparison to the rare complex disorder with a single etiology, such as syphilis.) Growing awareness of these challenges is reflected in a recent study conducted by the National Early Childhood Technical Assistance System (NECTAS), which revealed that a consensus is emerging on the importance of individualizing interventions to each child's developmental patterns and family needs (Hurth, Shaw, Iseman, Whaley, & Rogers, 1999).

RECOMMENDATIONS**Conceptual Framework:
A Functional Developmental
Approach**

The overriding, conceptual framework for all the following recommendations is a comprehensive, developmentally based model for assessment of and intervention with children with special needs, rather than restricted approaches limited to selected surface behaviors and cognitive processes. For complex syndromes, in addition to exploring

underlying etiological mechanisms, it is essential to work with the different functional developmental areas, including their deficits and strengths and the relationships among them. Full adoption of this *functional developmental approach* requires changes at a number of levels, including clinical services, special education, prevention and screening, national and community policies, and research. This chapter discusses these recommendations as well as challenges to them.

Components of a Functional Developmental Approach

In using a functional developmental approach, clinicians should include the following areas in an evaluation and intervention program.

- *Functional emotional developmental capacities*, which identify how the child integrates all her separate abilities (e.g., emotional, language, sensory modulation, spatial, and motor skills) to relate to the social and cognitive world in a purposeful and emotionally meaningful manner. They include the capacity to attend and regulate; relate to others; initiate purposeful interactions with gestures and/or emotional cues; engage in long, social, problem-solving sequences; create ideas, words, and imagine; and think, abstract, and learn. Mastering these critical functional developmental capacities depends on the child learning to connect her emotional interests, intent, or goals with her emerging motor-planning, cognitive, language, and sensory skills. These critical connections enable the child to create purpose and meaning in her world.

Children with complex developmental and learning problems, including autistic spectrum disorders, often only learn skills in an isolated, unpurposeful, or nonmeaningful way (e.g., memorizing scripts). They tend to have a harder time
- integrating these different capacities meaningfully. An appropriate intervention program must, therefore, focus not on isolated skills but on the most essential functional developmental capacities. Specific skills are embedded in these functional developmental foundations. More and more studies are identifying these capacities for shared attention, intimate relating, affective reciprocity, and the emotionally meaningful use of actions and ideas as the building blocks for logical and abstract thinking, including higher levels of empathy and reflection.
- *Individual differences in the functioning of the central nervous system*, with a special focus on how these differences are expressed in the way a child reacts to and processes experiences, as well as how she plans and organizes responses. This area typically includes sensory modulation (e.g., over- or underreactivity in each sensory modality, such as touch, sight, and sound); sensory processing (e.g., auditory [receptive language], visual-spatial, tactile, vestibular, and proprioceptive); motor planning and sequencing (e.g., planning and organizing actions, behaviors, and ideas); and other affective, cognitive, and learning processes (e.g., special talents and executive functions).
- *Child-caregiver interactions and family and service system patterns*, particularly as they mobilize developmental progress by working with the child's individual differences at the child's functional developmental level. In working with developmental, emotional, and behavioral problems, there is a tendency to lose sight of the functioning of the whole child and her family. Instead, the tendency is to work with isolated behaviors or processes (e.g., compliance, aggression, or matching shapes or colors), with insufficient attention paid

to the child's emotional relationship to her caregivers, her ability to engage in a continuous chain of back-and-forth affective and gestural interactions, or her capacity to generate creative ideas. For example, teaching a child to carry out a particular task in a rote manner may decrease her capacity for relating with joy and warmth, expressing a range of feelings, and communicating meaningfully.

In general medicine, it is axiomatic that all systems of the body are relevant and interrelated. Therefore, clinicians routinely assess all areas of functioning (e.g., kidney, liver, and other organ systems) when conducting an evaluation or assessing an intervention such as a new antibiotic.

A comprehensive program that deals with the whole child and his family (as well as his community and culture) provides a framework within which specific techniques that work selectively on different behaviors or areas of functioning can be employed. In fact, the same technique may be quite effective as part of a comprehensive approach and ineffective, or even deleterious, as an isolated intervention.

- *A team approach* to an individualized, comprehensive functional program that works with each child's unique pattern of functional deficits and strengths and often includes, as needed, speech therapy, occupational and/or physical therapy, special education, biomedical interventions, and mental health or developmental work with the child, and child-caregiver interactions and/or family patterns—with all team members working together.

A Functional Developmental Approach to New Interventions and Research

A comprehensive, functional developmental approach can guide the development

of new interventions. In a functional developmental approach, interventions developed for functional limitations in one syndrome can be applied to similar functional deficits even when they are part of another syndrome. For example, strategies developed by speech pathologists to facilitate expressive language by using oral-motor exercises can be employed with children with autism, fragile X and Down syndromes, and language dysfunctions. The same is true for strategies developed by occupational therapists to foster motor planning and sensory modulation. Such cross-syndrome applications favor innovation.

Research also can be defined by functional developmental areas rather than by only a specific syndrome. Autism research reviews (see Tsakiris, Chapter 31, this volume) can go beyond studies on children with autism and include research on different functional developmental problems across syndromes (e.g., motor planning, visual-spatial processing, sensory modulation, and auditory processing). Etiological factors and pathophysiologic pathways can be explored for each functional deficit (e.g., auditory processing and motor planning) as well as for whole syndromes. In short, given current knowledge, the best practice is for a team of clinicians to work with each child and family using a model that conceptualizes functional developmental deficits and strengths and constructs individually oriented clinical strategies based on all available knowledge from each of the disciplines that work with developmental problems (see Greenspan & Wieder, Chapter 4, this volume, for additional discussion of a comprehensive developmental approach to assessment and intervention).

Research Support for a Comprehensive Developmental Intervention Approach

In addition to clinical observational support, there is considerable research support

for an individualized, comprehensive functional developmental intervention approach. This support emerges from an examination of the complex nature of the intervention process and a careful scrutiny of the strengths and limitations of current research.

Nonbiological intervention research on autistic spectrum and other developmental disorders involving problems in relating, thinking, and communicating faces challenges similar to those the psychotherapy field has been struggling with for the past 40 years (Greenspan & Sharfstein, 1981). These include:

- Characterizing the aspects of therapeutic relationships that are efficacious.
- Validating what actually occurs in a complex intervention.
- Determining and measuring a broad range of relevant outcomes that relate to the important domains of human functioning rather than to a particular theoretical orientation.
- Delineating clinically meaningful subgroups to permit appropriate matching or randomization and interpretation of results (i.e., relating outcomes and patterns of progress to different clinical subgroups within a large heterogeneous disorder, such as autism).

There is, however, no comparative clinical trial intervention studies on the major interventions. Due to the lack of comparative intervention studies on different approaches, there is, at present, therefore, no way to tease out the therapeutically and educationally active elements from all the other elements. For example, several factors of an educational/therapeutic approach could be facilitating development, either individually or in combinations. One could hypothesize that it is the general attention, curriculum, support, or intensity (number of hours per week) of treatment that is having an effect. Alternatively, it

could be the therapist's or teacher's characteristics or personality, the amount of empathy and warmth, or the general practice effect (i.e., simply working on an area, such as speech or motor skills, or on a certain set of behaviors). It might also be a particular therapeutic or educational technique.

Furthermore, if the hypothesis is that a particular intervention technique is responsible for developmental progress, it is difficult to document that the technique is actually practiced in a reasonably similar manner by the different therapists and/or educators who are purporting to use the technique. Videotape studies of therapists performing their craft to separate out tactical variables from personality and relationship variables are rarely, if ever, carried out.

In addition, currently used outcomes in most intervention studies rarely cover the full range of important functional developmental capacities relevant to autistic spectrum and other developmental disorders. For example, few intervention studies have systematically intervened with and measured outcomes for joint attention and symbolic play deficits in children with autism (Mundy & Crowson, 1997), despite the fact that progress in these areas predicts positive outcome in longitudinal studies (Mundy, Sigman, & Kasari, 1990; Sigman & Ruskin, 1999) and deficits in these areas are clinical indicators for the disorder. Most intervention studies have not measured subtle aspects of abstract thinking, in-depth emotional and social functioning, and visual-spatial processing. Instead, these studies have focused on limited outcome variables related to IQ and circumscribed cognitive tasks. Reliance on benchmarks such as cognitive and language scores as sole indices of progress in interventions causes the more obscure, but ultimately more significant, constructs that rely on the integration of skills and abilities to be overlooked (Guralnick, 1991).

These constructs include reciprocity, shared pleasure, empathy, and other elements that are necessary for social competence, as well as arousal, emotional regulation, planning, organization, and attention that are involved in the executive processing of information (Casey, Bronson, Tivnan, Riley, & Spenciner, 1991; Guralnick, 1998; Klinger & Dawson, 1992).

The importance of including hard-to-measure outcome variables is supported by research showing that, when matched for IQ scores, individuals with autism compared to individuals without autism tend to show selective difficulties in the mental processes associated with higher-level abstract thinking capacities, such as the ability to make inferences, interpret information, generate new ideas or perspectives, and generalize (Minschew, 1997, 1999, in press), as well as empathize with and understand the perspective of others (Baron-Cohen, Tager-Flusberg, & Cohen, 1993).

Furthermore, most current intervention research does not create clinically meaningful subgroups within the autistic spectrum. These subgroups could be based on functional developmental capacities, such as social and affective reciprocity and level of symbolic functioning, individually different processing capacities (e.g., auditory processing, visual-spatial processing, motor planning), and child-caregiver and family interaction patterns (see Greenspan, Wieder, & Zimmerman, Chapter 16, this volume). Since children within the autistic spectrum differ, meaningful subgroups would permit teasing out an answer to the important clinical question: What approach is likely to be helpful for a given child and family with their own unique profile?

In summary, current research has not teased out the active therapeutic and educational ingredients, validated the techniques being practiced to determine what is actually being evaluated for efficacy, employed the broad range of outcomes necessary to measure

developmental capacities most relevant to autistic spectrum and other disorders of relating and communicating, or used clinically meaningful subgroups. In addition, as indicated, there are no comparative clinical trial outcome studies on the major interventions and no clinical trial outcome studies on comprehensive approaches showing clinically meaningful changes in the course of the disorder on a truly representative population of children with autism. At present, therefore, it would go beyond the currently available research to try to recommend interventions solely from research evidence, despite the fact that this is common practice for many educational systems (see Tsakiris, Chapter 31, this volume, for a more detailed discussion of these issues and a review of relevant intervention research).

The issue is, then, how can intervention programs be initiated without overstepping the existing data? Current research can provide important clues. These can be refined by clinical experience provided from the different disciplines working with developmental problems as well as by additional research. Together, research and clinical experience can provide a model to guide clinical practice. Such a model needs to move beyond which approach is best for a heterogeneous disorder and answer the more important question of how to develop interventions for a child who exhibits his own unique pattern of development and symptoms. It also must allow for, and encourage, a wide range of relevant research outcomes.

Creating the Basic Model

It is important to begin with a basic model that derives from both research and clinical experience. To do less runs the risk of providing less thoughtful interventions and of spending valuable research funds on studies of intervention programs that are unlikely to be helpful. For example, one may compare an

intervention that has a modest effect on approximately 30% of the children with autistic spectrum disorders with an intervention that has a modest effect on only 5% of the children. On the surface, it would appear that the intervention that modestly helps a third of the children is quite potent. However, the primary result of many confirmatory studies may be a well-documented intervention that is, nonetheless, unable to significantly help most of the children with the disorder. Alternatively, it is possible to begin with a robust model that builds on promising research and clinical practice observations. Such a model may create an opportunity to begin from a higher baseline and then study and fine tune an intervention model that is more likely to be helpful to more children.

There are a number of research and clinical practice observations that can contribute to conceptualizing a comprehensive developmental approach for autistic spectrum and other disorders of relating and communicating. One of these is the importance of working with the *different processing areas* compromised in these developmental disorders. These processing areas include work with (1) speech and language, which is well-documented in both research studies and clinical practice descriptions (Goldstein & Hockenberger, 1991; Law, 1997; McLean & Cripe, 1998; Wetherby & Prizant, 1993, 1995) and (2) the motor and sensory systems, including visual-spatial processing, which also is supported by research and clinical practice (Blackman & Goldstein, 1982; Case-Smith & Bryan, 1999; Chez, Gordon, Ghilardi, & Sainburg, 1995; Lincoln, Courchesne, Harms, & Allen, 1995; Williamson & Anzalone, 1997; Wachs, Chapter 20, and Feuerstein, Chapter 22, this volume).

There also is considerable research and clinical support for working with important *functional developmental capacities* (Greenspan, 1992; Tanguay, Robertson, & Derrick, 1998),

including attention and preverbal gestural interactive problem solving (e.g., joint attention [Mundy, Sigman, & Kasari, 1990]), reciprocal affective interactions (Dawson & Galpert, 1990; Lewy & Dawson, 1992; Tanguay, 1999), different levels of symbolic functioning in affective, interpersonal, cognitive, and language domains (e.g., theory of mind [Baron-Cohen, 1994] and the pragmatic [i.e., social functional] use of presymbolic and symbolic communication [Wetherby & Prizant, 1993]). These important areas of developmental functioning can be systematized clinically into six basic functional developmental capacities, which also have support from the normative child development literature (Greenspan, 1992; Greenspan & Lourie, 1981). These six functional developmental capacities are:

1. *Shared attention and regulation.*
2. *Engagement.*
3. *Affective reciprocity and gestural communication.*
4. *Complex presymbolic, shared social communication and problem solving, including imitation, social referencing, and joint attention.*
5. *Symbolic and creative use of ideas, including pretend play and pragmatic language.*
6. *Logical and abstract use of ideas and thinking, including the capacity for expressing and reflecting on feelings and having insights into self and others.*

A review of 200 cases of children with autistic spectrum disorders demonstrated that there were individual differences (i.e., variations) in these functional developmental and processing capacities among the children, further supporting the importance of working with them in the unique configuration that characterizes a given child and family (see Table 1) (Greenspan & Wieder, 1997).

There also is considerable support for focusing on *child-caregiver interactions and working with the family* (McCollum & Hemmeter, 1998; Krauss, 1998; Turnbull & Turnbull, 1982). In addition, two other elements appear to have importance. One is employing *a very intensive approach to working with children and their families*. In an intensive program, the majority of the child's time is involved in various types of

pleasurable, soothing, and learning interactions, leaving very little time available for self-absorption or perseverative activities. In most studies, the intensity factor (30 to 40 hours a week) appears to discriminate between greater and lesser outcomes (Lovaas, 1987; McEachin, Smith, & Lovaas, 1993; Scheinkopf & Siegal, 1998) at least in terms of IQ levels. This is the one finding of the Lovaas study that, based on the design,

| Functional Developmental and Processing Capacity | Percent of Patients | Description of Functional Developmental and Processing Pattern |
|--|----------------------------|---|
| Attention, engagement, purposeful and problem-solving behavior, and use of symbols | 24% | Partially engaged, purposeful problem solving, with limited use of symbols (ideas) |
| | 40% | Partially engaged, purposeful, with very limited complex problem solving, and inconsistent or no use of symbols |
| | 31% | Partially engaged with only fleeting purposeful behavior |
| | 5% | No affective engagement and minimal attention |
| Sensory modulation | 19% | Overreactive to sensation |
| | 39% | Underreactive to sensation (with 11% craving sensation) |
| | 36% | Mixed reactivity to sensation |
| | 6% | Not classified |
| Motor-planning dysfunction | 52% | Mild to moderate motor-planning dysfunction |
| | 48% | Severe motor-planning dysfunction |
| Low muscle tone | 17% | Motor-planning dysfunction with significant degree of low muscle tone |
| Visual-spatial processing dysfunction | 22% | Relative strength (e.g., can find toys, good sense of direction) |
| | 36% | Moderate impairment |
| | 42% | Moderate to severe impairment |
| Auditory processing and language | 45% | Mild to moderate impairment with some abilities to imitate sounds and words or use selected words |
| | 55% | Moderate to severe impairment with no ability to imitate or use words |

can be supported clearly and unequivocally. The Lovaas study compared a 40-hour per week intervention program with a 10-hour per week intervention program and found the more intensive program was associated with better outcomes in regard to IQ and selective adaptive scores.

However, defining the active ingredients of a more intensive approach and the threshold levels of very intensive programs is not yet clear from available research (Rogers & DiLalla, 1991; Venn, Wolery, & Graco, 1996; Zelazo, 1997). Intensity is not defined just by the number of hours spent in one-on-one instruction, but also by the amount of time spent during a child's day in helping him generalize skills through the more spontaneous experiences and interactions of daily life and the classroom.

It also appears that *one-on-one child-caregiver interactions*, especially for children who are not yet social and interactive, is essential for significant progress (Dawson & Osterling, 1997; Powers, 1992). Additionally, as children become available for social interaction, it appears that balancing adult-child one-on-one work with peer-to-peer and small-group work is also quite helpful (Hoyson, Jamison, & Strain, 1984; Strain & Cordisco, 1994).

The Developmental, Individual Differences, Relationship-Based (DIR) Approach

The promising elements just identified can be conceptualized as part of a comprehensive developmental model (Greenspan, 1992; Greenspan & Wieder, 1998, 1999) by systematizing the elements into the three broad categories described in a previous section. These broad categories are:

1. **D** – *Developmental capacities* that integrate the most essential cognitive and affective processes. These are the six func-

tional developmental capacities described previously on page 18 of this chapter.

2. **I** – *Individual differences* in motor, auditory, visual-spatial, and other sensory processing capacities.
3. **R** – *Relationships* that are part of child-caregiver and family interaction patterns and which provide:
 - ongoing nurturing support;
 - orchestration of the specific educational and therapeutic elements incorporated in 1 and 2 above;
 - provision of ongoing interactive learning opportunities geared to the child's individual differences and current functional developmental capacities throughout most of the child's waking hours (at an appropriate intensity); and
 - a balance between one-on-one caregiver-to-child interactions and peer-to-peer interactions appropriate to the child's individual differences and functional developmental capacities.

In the Developmental, Individual Differences, Relationship-based (DIR) approach, functional developmental capacities, individual differences in processing capacities, and relationships embedded in the child-caregiver and family patterns are utilized together in clinical decision making to create an individualized program for a given child and family.

In conclusion, there is a wide range of research and clinical experience not just from the field of autism but from the field of early intervention and child development at large, which, when taken as a whole, provides considerable empirical support (far more than for more circumscribed approaches) for a comprehensive developmental model.

The Challenge to a Functional Developmental Approach

Restrictive frameworks that ignore a child's relevant processing capacities, critical functional developmental abilities, necessary family support, and involvement of all relevant disciplines present a special challenge. Although there are many types of restrictive approaches, two are especially visible and often are mistakenly presented as comprehensive. One involves using applied behavioral analysis (ABA), or discrete trial behavioral approaches, as a primary approach rather than as one possible part of a comprehensive effort. In this approach, limited areas of behavior are targeted for modification. The full range of functional developmental deficits and strengths is often not assessed or worked with, nor is the expertise of key professionals sought to facilitate development in these critical areas of functioning (i.e., occupational therapists or speech pathologists are not typically involved in a discrete trial behavioral program). In-depth family and child-caregiver dynamics also are often not a part of this framework.

ABA was the first method to advocate hopeful, intensive one-on-one work and, for a long time, was the only approach to work in this way. During the last 15 years, however, as indicated earlier, there is new research and understanding of differences in underlying processing capacities, the functional developmental capacities that lead to intelligence and emotional health, and the importance of emotions, spontaneous child-caregiver interactions, and family patterns for healthy development. These findings have enabled the field to progress beyond a focus on discrete behaviors and construct intensive, one-on-one and small-group approaches that are comprehensive, developmentally based, and tailored to the

individual profile of the child and his or her family. Within such a broad developmental framework, behavioral techniques can be used when needed as part of a larger comprehensive program. For example, children with severe motor-planning problems who are having difficulty learning to imitate motor actions, sounds, and/or words may benefit from more structured work. Behavioral analysis of the environmental factors influencing adaptive and problem behaviors and some of the newer behavioral approaches that focus more on spontaneous or incidental learning opportunities can also be helpful for particular children at a specific time in their development as part of a comprehensive program. Behavioral approaches in and of themselves, however, should not be the primary organizing approach for a program. The primary approach should use a broad developmental framework that conceptualizes all of the vital developmental processes.

In many treatment programs and educational settings, however, behavioral approaches are still used as the primary approach. At times, proponents of ABA (discrete trial) approaches go beyond the available data in discussions of their effectiveness. It is, therefore, necessary to briefly examine the limitations of the research on these approaches.

Proponents of discrete trial behavioral approaches cite the longitudinal Lovaas study (Lovaas, 1987; McEachin et al., 1993) and a number of shorter-term studies. Many professionals and organizations, however, point out the limitations of these studies (Bristol et al., 1996; Greenspan, 1998; Gresham & McMillan, 1998; Rogers, 1996; Schopler, 1987). The Lovaas study had many limitations. Most important, it did not include a representative sample of children with autism. The selection criteria eliminated chil-

dren who presented with the most typical autistic patterns and, instead, only allowed children who evidenced certain cognitive capacities and had better prognoses. Furthermore, the study used limited outcome measures, focusing on the children's performance on selected, structured, cognitive tests. These tests, however, do not distinguish autistic and nonautistic individuals who are matched for IQ. The outcome measures did not sufficiently assess the variables that research has shown to distinguish autistic and nonautistic individuals and that are specific to autistic functioning. When autistic and nonautistic individuals are matched for IQ, the autistic group shows deficits in the capacity for higher-level abstract thinking, such as making inferences and creating new ideas and solutions (Minsheu, 1997, 1999, in press), and understanding one's own and others' feelings (Baron-Cohen et al., 1993). The autistic group also shows deficits in emotional reciprocity and shared attention (Baranek, 1994; Dawson, 1992; Dawson & Galpert, 1990; Lewy & Tanguay, 1999; Mundy et al., 1990; Osterling & Dawson, 1994). The outcome measures used in the Lovaas studies, however, did not assess these autistic-specific deficits involving abstract and creative thinking and emotional flexibility, awareness, and relatedness. In addition, the children in the comparison group did not have precisely the same cognitive and social functioning as the intervention group at the start of the study, the study did not involve random assignment, and participants knew the group to which they were assigned. Furthermore, in another study of discrete trial behavioral interventions with children with more typical patterns of autism involving severe cognitive deficits, the results were not encouraging. Although the intervention group did better than a control group, the changes in the children's behavior did not pass clinically mean-

ingful thresholds; that is, the children retained most of their autistic patterns (Smith, Eikeseth, Morton, & Lovaas, 1997). Furthermore, behavioral studies that show short-term, selected behavioral changes do not sufficiently look at long-term, clinically meaningful changes in important areas of functioning such as empathy and creative, logical, and abstract thinking—the areas of functioning that are impaired in autism.

The limitation of the ABA-discrete trial and related behavioral approaches as the primary approach is perhaps best illustrated, however, by contrasting its wide use in various forms in educational and other settings in most communities during the past 25 years with the lack of progress by most children receiving these approaches. The majority of children with typical patterns of autism in behavioral programs generally have been unable to learn to live independently, work, and participate in a range of age-expected social relationships.

The question then becomes: Should many clinicians and educators continue to use a primary approach that is restrictive, that evidence suggests is of limited value, and that excludes emerging, promising knowledge from the different disciplines, such as occupational therapy and speech pathology? Or, is it time for the entire field to progress to a broader-based approach through which all the knowledge available from different disciplines and levels of research can be used and interventions can be tailored to the child's profile of functional developmental deficits and strengths? This dilemma is not just of theoretical interest. The New York State Department of Health, based on what could be a serious misreading of current research on interventions (see Tsakiris, Chapter 31, this volume), has recently issued a report recommending the restrictive behavioral approaches as a primary approach. The recommendations in that report may severely

limit the services available to children and families when developmental problems are present.

The second restrictive approach that is widely used and often mistakenly presented as comprehensive is for a therapist to work with only a limited number of a child's cognitive skills, on the assumption that these are the only skills relevant to a community's educational responsibilities. Typically, such a restrictive educational approach focuses on a very limited number of surface behavioral, cognitive, and social goals, such as rote behaviors or phrases, matching exercises, and social compliance. Only a minimal amount of speech or occupational therapy is provided to work on a child's underlying processing problems.

In a field of incomplete knowledge and no definitive comparative intervention studies, a clinician can provide each child and family the best possible approach only when the option is available to orchestrate a broad-based developmental approach tailored to each child's unique profile of functional developmental deficits and strengths.

The next sections present a series of additional recommendations on the implementation of an appropriate assessment and intervention program, including needed changes in current policies. Subsequent chapters will further amplify these and related recommendations. (See Appendix A of this chapter, "Outline of the DIR Model: How to Use *The ICDL Clinical Practice Guidelines*" for a schematic outline to the functional developmental approach to assessment and intervention.)

Assessment Program

Recommendations For Assessment

- *A comprehensive developmental approach.* A comprehensive individual or team-based approach involves all the relevant

functional areas, including a child's individual processing differences, functional developmental level, child-caregiver interactions, and family functioning. A clinician must observe these areas of functioning for a reasonable period of time, with special emphasis on the child's interaction with primary caregivers in order to assess the child's capacity to relate to others and to tease out the full degree of the child's strengths and challenges. A recent chart review of 200 cases revealed that more than 90% of evaluations, including evaluations conducted at university medical centers, clinics, educational settings, and individual practitioners' offices, did not include direct observations of child-caregiver interactions for longer than 15 minutes (Greenspan & Wieder, 1997). In these settings, there tends to be an emphasis on administering structured tests with insufficient attention given to child-caregiver interactions and family functioning.

- *A clinical evaluation process.* Assessment should be the initial phase as well as part of an ongoing clinical process of observation and discussion. The evaluation of infants and children with disorders of relating, communicating, and thinking is a complex process involving careful reports of a child's current developmental functioning, a detailed developmental history, and direct observations of the child interacting with parents as well as the clinician, with a focus on the child's six primary functional developmental capacities, individual processing differences (e.g., motor planning, auditory and visual-spatial processing, sensory modulation), and interaction patterns with caregivers and other family members (see Greenspan & Wieder, Chapters 4 and 15, this volume). Additional assessments must build on this clinical core and often may include assessments of language,

motor and sensory functioning, visual-spatial capacities, and different cognitive skills, as well as a biomedical evaluation.

The evaluation process must also include a careful review of family functioning, including discussion with the parents about family relationships and the ability of the family to support the child's different functional developmental capacities as well as work with processing vulnerabilities. In addition, for children with significant developmental challenges, the evaluation process must create a working relationship between the family and the clinician(s) conducting the evaluation. If an intervention is recommended, this relationship will facilitate the family's transition into an intervention program. The working relationship emerges from an understanding of family patterns and a consensus between parents and clinician(s) on the child's developmental profile. An extended evaluation may be required to reach consensus and enable a family to support a comprehensive, individually tailored intervention program.

Although observation and discussion are at the core of the evaluation process, structured protocols and developmental tests may play a supplementary role if needed for a particular child and family. There are a number of reasons why structured assessment protocols or developmental tests should not be used as the primary core of the assessment process. At present, there is not sufficient evidence that they can elicit the full cooperation of a child with severe developmental challenges (i.e., bring out the child's highest level of functioning in each capacity). In addition, there is also insufficient evidence that they can address the range of subtle distinctions during all the phases of infancy and early childhood in critical

functional developmental capacities and important processing abilities (e.g., visual-spatial, motor planning, sensory modulation) more effectively than a comprehensive clinical evaluation utilizing observation, discussion, and clinical judgement. At present, therefore, structured tools should be reserved for research (to establish common ground for a diagnosis) and/or to supplement, on an as-needed basis, the core clinical evaluation.

- *Diagnosis should be a dynamic, ongoing process involving a functional developmental profile of the child and the child's family.* Syndrome-based diagnoses, if required, should initially be provisional and play a secondary role unless the syndrome involves a clear etiology, biologic pathway, and highly effective treatment.
- *In addition, diagnoses of syndromes such as autism and mental retardation should be made only after working with a child for a significant time interval in an optimal program and after observing the child's response to intervention.* Children who quickly learn to relate and interact, for example, may not require a diagnosis of autism even if they initially meet the criteria. Similarly, a diagnosis of mental retardation, which suggests chronic, fixed, global deficits, should not be made unless a child's ability to learn has leveled off for 2 to 3 years in spite of an optimal, individually tailored program. During the time a clinician spends on observation of a child, services can be justified either by the degree of the child's functional deficits that can be documented or with a "provisional" diagnosis.
- *Distinguishing specific and nonspecific symptoms in autistic spectrum disorders is essential to making a proper diagnosis.* With an increasing number of children being diagnosed with autistic spectrum

disorders, clinicians and parents are understandably attempting to identify this problem as early as possible. Proper early identification, however, requires a clear understanding of the nature of the deficit that is specific to the disorder and the ability to distinguish this deficit from symptoms seen both in autism and other disorders (i.e., nonspecific symptoms). The deficit that is specific to autism involves the inability to relate to caregivers and engage in a continuous flow of back-and-forth (reciprocal) affective gestures in a variety of contexts (e.g., flirting, getting help and collaborating to solve problems, seeking admiration or approval, or pointing out something of interest).

A common mistake, however, is to make the diagnosis of autism based on a symptom or group of symptoms that are not specific to autism; that is, symptoms that are found in many developmental and learning problems. Examples of symptoms or behaviors that are seen in both autism and other disorders—but are often mistakenly thought to be specific to and, therefore, a sign of autism—are hand-flapping, echolalia, perseverative or repetitive behavior, difficulty relating to peers, and problems with understanding one's own and others' feelings (i.e., the capacity for empathy or theory of mind). Hand-flapping and other unusual motor behaviors can be seen as part of a variety of motor-planning and coordination difficulties, particularly during times of excitement. Echolalia is often seen as part of receptive language problems, in response to which the child may repeat what he hears both because he has difficulty processing it and to hold it in mind as a first step in processing it. Repetitive behavior is often seen in children who tend to become overloaded by sensory

input combined with dyspraxia (motor planning problems). Peer problems can be seen in children who lack opportunities to practice relating to peers, are sensory under- or overreactive, are very anxious, have receptive language problems, or who have severe motor-planning difficulties. Problems with empathy and theory of mind can be seen in many children with severe receptive language, cognitive, regulatory, and/or antisocial behavior problems.

Children who are capable of engaging caregivers with deep intimacy and can participate in a continuous flow of affective (gestural) signaling in a variety of problem-solving contexts are, at times, misdiagnosed with an autistic spectrum disorder because of the presence of some of these nonspecific symptoms. Based on a misdiagnosis, they may be placed in an inappropriate treatment program (e.g., a very controlled and repetition-oriented behavioral or educational program that does not sufficiently emphasize affective relationships and dynamic problem solving interactions) that can undermine their very strength, which is the ability to relate to and reciprocate with a range of affective signals and gestures (i.e., communicate purposefully and creatively). Therefore, only the deficits that are specific to autistic spectrum disorders should be used as primary criteria in making a diagnosis. As indicated earlier, however, working with a child over a period of time is the best way to observe the extent and degree to which a child evidences and can change these primary autism-specific deficits.

Challenges to the Recommendations for Assessment

- *Special challenges to the assessment recommendations include approaches that*

focus on limited areas of functioning and/or isolated surface behaviors and do not assess and fully incorporate underlying individual processing differences, spontaneous child-caregiver interactions, the intimacy and affective reciprocity involved in the child-caregiver relationship, or in-depth family functioning.

- In addition, *developmental test-oriented evaluations, which do not fully assess child-caregiver interactions or family patterns*, may omit important observations that are essential for planning interventions. While developmental tests may be part of a comprehensive approach, IQ or other structured developmental tests should not be used as a primary way to categorize or label children or organize an intervention program. While such tests have a long tradition behind them, they may only measure selected cognitive capacities at a point in time. Furthermore, they do not measure all the critical processing capacities that relate to intellectual functioning. In addition, performance on them can be undermined by selective processing deficits such as severe motor-planning and sequencing problems. For example, we have clinically observed children with severe motor-planning and sequencing problems improve their performance on IQ tests by 30% to 50% during a 5-year period as their motor planning and sequencing improved (Greenspan, 1992; Greenspan & Wieder, 1998). IQ and other structured developmental tests, therefore, should not take the place of observing a child over time as he learns through interactions tailored to his developmental profile of processing strengths and weaknesses. In fact, labeling a child and treating him as though he is similar to others in his category tends to decrease the likelihood of

individualized learning interactions. In contrast, working with a child and constantly attempting to find better and better ways to understand his differences and create dynamic, individualized learning interactions often creates continuing opportunities for growth.

- Therefore, *time- and context-limited evaluations that do not include or integrate observations of the child's functioning over time in multiple contexts*, including the child's response to a comprehensive intervention program, may unnecessarily limit the scope of needed observations.

Intervention Program

Recommendations for Intervention

- *A Development, Individual Differences, Relationship-based (DIR) approach*. The intervention program must work with all essential functional developmental capacities (regulation and attention, engagement, two-way purposeful interaction, problem-solving interactions, the creative use of ideas, and logical thinking), individual processing differences (auditory, language, visual-spatial, motor planning, and sensory modulation), and child-caregiver interactions and family functioning, as well as additional cognitive and learning skills. The functional developmental intervention model, which is described more fully in Chapter 4 of this volume, is characterized by a number of additional features.
- *Three types of learning involved in a comprehensive functional developmental intervention program*. The first type of learning involves following the child's lead and engaging in child-initiated interactions that are based on the child's natural emotional interests (floor time). The goal of these spontaneous interactions is

to mobilize and improve attention, engagement, purposeful and problem-solving interactions, and, if the child is ready, the creative and logical use of ideas and words. The second type is semistructured problem-solving interactions that meet specific language, cognitive, and social goals. An example of this is an adult enticing a child to try to open a door to get a favorite toy, and using the child's motivated state to teach her to say "open." Semistructured learning can also be relatively structured, if needed. A child with severe challenges in motor planning and sequencing that are interfering with his capacity to imitate and use words, for example, will often require, together with dynamic interactions, a very structured program for a period of time to strengthen motor planning and imitative capacities. Techniques worked out by Arnold Miller (see Miller & Eller-Miller, Chapter 19, this volume) and many of the imitative exercises developed through behavioral approaches can be especially useful in this circumstance. For children unable to engage in complex verbal or gestural interchanges, but with relative strengths in visual pattern recognition, elements of the TEACCH program, which emphasizes visual processing, may be especially valuable. Each of these structured elements, however, needs to be embedded in a comprehensive, functional developmental program that works with all the child's important functional capacities and his family relationships. The third type of learning that characterizes a functional developmental intervention program is motor, sensory, and spatial learning activities oriented toward facilitating motor planning and sequencing, sensory modulation, and visual-spatial thinking. (See Greenspan & Wieder,

Chapter 12, this volume, for a more detailed description of the three types of learning interactions.)

- *All-day and evening programs.* Children with severe developmental problems, including autistic spectrum disorders, often cannot, on their own, initiate or carry through developmentally appropriate interactions or learning practices as recommended by the National Association for the Education of Young Children (NAEYC). If left alone, children with developmental challenges may perseverate, become self-absorbed, or self-stimulate. Therefore, they often require one-on-one or small-group interactive and learning opportunities throughout their waking hours, either in school or at home, geared to their unique developmental profiles. These should include relationship-based interactive, relaxing, and soothing times.
- *Individual therapies,* including speech and language and occupational and/or physical therapy at *sufficient intensity (based on the child's developmental profile) to facilitate optimal progress.* Often, three or more individual sessions of 45 minutes each is required for each therapy.
- *Integrated education program and peer interaction and play opportunities.* Once children with special needs can imitate gestures, sounds, and words, and interact with others, they often benefit from an integrated education program. If they are in a home-based educational program, they benefit from daily opportunities for substantial social interaction during which the other children can understand and respond to their communications. They also require four or more one-on-one peer play dates a week. The education program at school or at home should also be based on the three types of learning described earlier in one-on-one and small-group contexts. In this

way, the child can learn through ongoing interactions with others rather than in isolation or through watching.

- *An appropriate education program.* The child's Individual Education Plan (IEP) should include the main functional developmental capacities of attention and regulation, engagement, purposeful two-way circles of communication, problem-solving interactions, the creative use of ideas, and the capacity to build logical bridges between ideas, as well as work on each processing capacity (i.e., audit, visual-spatial, motor planning, and sensory modulation) as the primary goals. Often, a child can master these developmental goals in conjunction with specific academic or pre-academic skills.
- *Biomedical approaches* should be tailored to each child's individual differences and developmental capacities, including consideration of medication and/or nutritional approaches.
- *Technology-based learning opportunities* should be geared to each child's individual profile.
- *Consultations by a developmental and/or mental health specialist to help construct and monitor the overall program* including the three types of learning and child-caregiver and family interactions.
- *A full evaluation and, if required, an intervention program should be initiated immediately if functional developmental capacities, as outlined in the screening approach are not progressing* (see Appendix B, Figure B1, this chapter, for the Functional Developmental Growth Chart). A wait-and-see approach should only be an option for a short period of time and for circumscribed difficulties that do not interfere with relating, functional communication, or thinking.

- *An intervention program should offer the potential of continuity.* The typical change from an infancy to a preschool program at age 3 is often disruptive for children who are working on learning to relate to others and trust relationships.

Challenges to the Recommendations for Intervention

- Special challenges to the preceding recommendations include *approaches which purport to be comprehensive but which do not work with the most relevant functional developmental capacities and related family patterns.* Noncomprehensive approaches include *programs that only work on isolated behaviors and/or language and cognitive skills* and do not sufficiently help a child master core functional capacities, such as shared attention, relating, reciprocal affective cueing, self-initiated problem solving, and the creative, logical, and meaningful use of ideas, or strengthen underlying processing difficulties, or work on relevant family patterns. Therefore, noncomprehensive interventions—which include behavioral and limited educational approaches—should not be used as the primary intervention program for children with disorders of relating, thinking, and communicating, including autistic spectrum disorders. As indicated earlier, however, elements of various approaches may be incorporated into a comprehensive developmental approach tailored to a child's unique profile.
- Further challenges to these recommendations include *programs that are not sufficiently intensive, do not create necessary one-on-one and small-group learning opportunities, and do not contain sufficient learning or interactive opportunities for the child's day and evening time.*

Many children require one-on-one and/or small-group interactive learning opportunities throughout the day and evening in their school and home programs. Too much time spent alone or watching television, as well as passive observation of other children, often results in a child's increasing self-absorption, perseveration, and lack of adequate progress. Some states, such as Pennsylvania, provide "wrap-around" services that can be tailored to the child's developmental profile to help parents create an appropriately intensive home or after-school program.

Prevention and Monitoring Development

Recommendations for Prevention and Monitoring Development

- *An early, universal, prevention and developmental monitoring program.* Through routine well-baby and child pediatric care, early education, daycare, public health and education dissemination efforts, and other programs, all families with children should have access to information, advice, support, and back-up clinical services to promote the child's mastery of (and prevent difficulties in) each expected functional developmental capacity. As part of these efforts, every parent should be offered help to identify the child's emerging functional developmental strengths and challenges.
- *There should be three levels to this program.* At the first level, a series of readily observable functional milestones that integrate the different important functional developmental capacities can be used for observing and asking questions about an infant and child's development as part of well-baby and child care, in early educational settings, and by parents. At the

second level, if needed, a more detailed screening questionnaire can be used to further document a potential problem and determine if a full evaluation is needed. At the third level, if needed, a full evaluation should be conducted and an appropriate intervention program should be available. (See Appendix B, this chapter, for the Functional Developmental Growth Chart and Questionnaire.)

The Challenge to Recommendations for Prevention and Monitoring Development

A special challenge to the preceding recommendations is a *wait-and-see approach that does not distinguish serious emerging functional developmental deficits from circumscribed challenges that the child and family may master on their own.* Waiting to see if a child "grows out of it" is not recommended when critical functional areas, such as relating, interacting, or communicating, are involved because these critical capacities build on one another and are much harder to master later in development. When critical capacities are not developing, delay in evaluating or implementing appropriate interventions tends to increase the challenges. In contrast, circumscribed difficulties, such as a mild expressive language articulation problem, may be observed for a short period of time to see if the difficulties diminish on their own or after advice to parents.

Community and National Policies Affecting Children and Families with Special Needs

Policy Recommendations

Full implementation of the comprehensive functional developmental approach recommended here would require changes to several community and national policies.

Appropriate policies would stress the following actions:

- *Early identification and intervention for functional developmental impairments.* Early intervention minimizes a child's ongoing functional developmental impairments and missed opportunities for mastering critical skills.
- *Flexible criteria for early intervention services.* Resources should not be used to "guard the door." Parents, pediatricians, or developmental specialists should determine if interventions are needed based on their potential to help a child, not on the child's degree of impairment. Most parents will not seek unneeded services, and children in the "gray areas" will be less likely to need intensive services later if help is provided early.
- *Parental involvement.* Parents should be leaders or co-leaders at all levels, including planning an intervention program for their individual child.
- *An "optimal," rather than "adequate," standard for education and special education.*
- *Equality of insurance coverage with other medical disorders, including all recommended therapies, for developmental disorders.*
- *Programs that tailor the approach to the unique characteristics of the child and the child's family rather than having the child and family fit to the program.*
- *Special curricula and programs for pre-professional training based on a functional developmental model.*
- *An emphasis within the training programs of various disciplines to include cross-training in the theories and techniques of other professions.*
- *Efforts to help programs with different philosophies embrace a comprehensive developmental framework and work together so that, when appropriate, ele-*

ments of different programs can be harnessed to meet the individual needs of a given child and family.

- *Recognition of the lack of a single etiology for most non-progressive, complex developmental disorders, including autistic spectrum disorders.* Therefore, support is needed for a broad range of program options with efficacy reviews based on functional developmental areas, and on different levels of knowledge. Practitioners and parents should then determine the type of program for a particular child based on that child's unique profile.

Challenges to the Recommendations for Policy Changes

- Challenges to the preceding policy recommendations include *adversarial interactions between educational or service system professionals and parents.* These conflicts often stem from attempts to justify an "adequate" rather than "optimal" program model or to delay the initiation of appropriate intervention services.
- Challenges also include *restrictive policies supporting a particular intervention approach rather than generic support for constructing an individualized approach that will be best for a particular child* (see Tsakiris, Chapter 31, this volume).

Research

Research Recommendations

- *Research into the etiology and biological pathways involved in autism and other disorders of relating, communicating, and thinking should focus on the etiology and biological pathways associated with specific functional developmental deficits, such as in the connection between affect and motor planning and symbol formation, visual-spatial thinking, motor plan-*

ning and sequencing, and auditory processing, as well as entire syndromes.

Because children with autism and other disorders of relating, communicating, and thinking differ a great deal from one another in their functional developmental capacities, it is highly likely that we are dealing with heterogeneous disorders with many subtypes. Therefore, in order to make sense of biological findings, *more research must be conducted on constructing subtypes based on functional developmental patterns* (see Greenspan & Wieder, Chapter 16, this volume).

There are many clinical challenges affecting large numbers of children that are under-researched. These include self-absorbed, aimless, and fragmented patterns of relating and communicating for preverbal children and concrete, rigid, polarized, and constricted ideational patterns for verbal children. They also include problems in motor planning, visual-spatial thinking, auditory processing, and sensory modulation.

- *Exploratory research in the different disciplines to generate improved clinical strategies is needed.* At present, there is support for evaluation and outcome research but not for research to generate clinical intervention strategies worthy of being evaluated.
- In addition to exploratory studies, *there is a need for comparative clinical trial studies of the major intervention models.* Such studies would help the field identify the critical therapeutic variables by controlling for such factors as intensity and positive expectations.
- *A cumulative central nervous system challenge model should guide a significant portion of the research effort* because the causes and pathways involved in autistic spectrum and related

disorders of communicating, relating, and thinking include the interactions among many factors. Among under-researched factors that need to be studied in interaction with each other are genetic susceptibility and prenatal exposure to toxic substances, such as dioxin and PCBs. These toxic substances, which are associated with increased risk of developmental, immunologic, and reproductive dysfunction, are found in soil, air, water, and, surprisingly, at unsafe levels in maternal breast milk in the United States and most industrialized countries. Other factors that need greater study are postnatal precipitants of regressions in developmental functioning, which occur in one-third to two-thirds of children diagnosed with autistic spectrum disorders (e.g., autoimmune phenomena, various types of physiologic and/or psychological stress). It is likely that genetically susceptible children undergo a series of insults, as just described, which present cumulative challenges to the central nervous system, resulting in developmental regressions and various symptoms of sensory, language, cognitive, affective, and motor dysfunctions.

- *The field must refrain from overstepping current research and advocating narrow “evidence-based” guidelines for clinical practice and, instead, advocate broad knowledge-based guidelines that utilize both available research and clinical experience.*

Acknowledging limitations in the evidence, however, far from leaving the field of interventions for developmental problems vulnerable, creates an important foundation for progress. A number of important facts are part of this foundation. One is that over 20 years ago there was already overall support for the value of early intervention for developmental prob-

lems (Greenspan & White, 1987; White and Greenspan, 1987). But historically as well as in the last 20 years there is not sufficient data on specific interventions. Nor are there enough comparative studies on different interventions for the same problem. Therefore, the critical question on which approach will work best for an individual child with a unique developmental profile cannot be answered with definitive data. The proper scientific approach in such a circumstance is to develop broad, knowledge-based guidelines rather than narrow, evidence-based ones.

There are four criteria based on clinical experience that can help determine if there is sufficient evidence for truly evidence-based clinical guidelines:

1. There are a sufficient number of outcome studies on representative populations of the disorder. These studies include different clinical subtypes and use a clinical trial methodology to draw definitive conclusions about relative efficacy.
2. Differences between the intervention group and the comparison group meet a clinically meaningful threshold; that is, they constitute significant gains in the core functional developmental areas germane to the disorder.
3. Interventions are clearly definable. Their operative elements can be identified, measured, and verified, and alternative hypotheses about the operative elements can be ruled out.
4. The disorder is sufficiently understood, including the relationship between its components and its causes. If it is a complex disorder, the interventions can be related to the range of underlying processing deficits and individually different pat-

terns and modes of expression, in addition to surface behaviors.

At present, intervention research on disorders of relating and communicating (e.g., autistic spectrum disorders) do not meet these criteria. Therefore, a broad knowledge-based approach is needed to inform current research and guide clinical practice.

Challenges to the Recommendations for Research

- *The clinical practice and research cultures need to work together more effectively.* Building a body of clinical knowledge needs to draw upon both available research and the expert opinion of all the clinical disciplines working with developmental disorders. A working partnership between the cultures of research and clinical practice could clearly move the field forward. There are a number of challenges, however, to the research and clinical practice cultures being able to work together as fully as possible. The culture of clinical practice is guided by day-to-day clinical challenges. It employs clinical reasoning and decision making, based on an understanding of the nature of the disorder, clinical experience with a range of cases, expert opinion, and available research. The culture of research, although guided by clinical challenges, is defined by available methodologies, data sets, and funding. Areas of developmental functioning and intervention techniques that available research methods are unable to quantify or that have not been identified by existing data sets, or simply lie outside current funding priorities, may be left unstudied, even though they have enormous clinical implications. By its nature,

therefore, research contributes more fully to some areas of clinical practice than to others. In general medicine, for example, research often provides helpful data on circumscribed potent interventions, such as specific pharmacologic interventions or defined surgical procedures. Interestingly, however, even for well-defined disorders and interventions, there is rarely enough research on clinical subgroups within a broad diagnostic category to guide clinical management decisions for an individual patient. Clinical experience, in the form of expert opinion, is still required.

Expert opinion based on clinical practice and an understanding of the disorder in question, together with available research, is especially important in the clinical management of complex disorders that are only partially understood. These disorders make up the bulk of clinical practice and include the treatment of conditions such as heart disease and diabetes. For example, for more than 20 years, clinicians recommended tight control of blood glucose for diabetes treatment, based on case studies and an understanding of the pathophysiology of diabetes. Only recently was this clinical management decision confirmed by a large, federally funded study.

Most developmental disorders involving problems in relating and communicating, including autistic spectrum disorders, fit into this group of complex, partially understood disorders that require long-term clinical management.

- *To improve knowledge for the treatment of complex developmental disorders, including autistic spectrum disorders, the research and clinical practice communities will need to work together on a number of levels.* The clinical practice community will need to use case studies

and collections of cases to systematically describe problem areas, different functional capacities, intervention methods, and relative courses of progress. As indicated, in the history of medical practice, there is a long tradition of employing expert opinion to discuss and systematize clinical principles in the face of incomplete, but developing, knowledge. The research community will need to apply rigorous methods at the current level of limited knowledge and build from there, working closely with the emerging body of clinical descriptions.

Specifically, clinicians and researchers will need to work toward the following goals:

1. Descriptive case studies to identify more fully all the relevant functional areas derailed in developmental disorders.
2. Exploratory clinical case studies to develop improved assessment and intervention methods for the clinically relevant functional areas.
3. Program descriptions to identify potentially helpful therapeutic elements.
4. Descriptive intervention studies (initially without necessarily involving control groups) to identify promising approaches that appear to facilitate a better-than-expected developmental course for a particular disorder.
5. Methods-development studies to improve techniques to measure difficult-to-quantify developmental and intervention variables.
6. Refinement of assessment and intervention practices based on in-depth clinical descriptions of a wide range of clinical cases.
7. Determining when intervention strategies are sufficiently developed and

helpful to warrant large-scale definitive clinical trial outcome studies.

8. Clinical trial intervention outcome studies for those interventions and areas of functioning that preliminary studies have identified as sufficiently promising to warrant this type of study.

SUMMARY OF A FUNCTIONAL DEVELOPMENTAL APPROACH PROGRAM ELEMENTS

Chart 1 is a brief summary form looking at whether or not a program incorporates the preceding recommendations in its capacity to offer assessments and interventions tailored to the unique developmental profile of each child and the child's family. ■

Chart 1. Report Card on Assessments and Interventions for Complex Developmental Problems, Including Autistic Spectrum Disorders

| | YES | NO |
|---|--------------------------|--------------------------|
| Does the assessment program include all the relevant functional areas? | <input type="checkbox"/> | <input type="checkbox"/> |
| Does the assessment include significant observations of parent-child interactions and family functioning over time and in multiple contexts? | <input type="checkbox"/> | <input type="checkbox"/> |
| Is there a functional developmental observation and screening program for all infants and children? | <input type="checkbox"/> | <input type="checkbox"/> |
| Does the intervention program work with all the relevant functional areas, as well as child-caregiver and family interaction patterns? | <input type="checkbox"/> | <input type="checkbox"/> |
| Does the intervention program provide a home-based, intensive after-school or full-day program of developmentally appropriate interactions? | <input type="checkbox"/> | <input type="checkbox"/> |
| Are appropriate therapies, such as speech and language and occupational and/or physical therapy, offered at sufficient intensity (e.g., 3 times/week)? | <input type="checkbox"/> | <input type="checkbox"/> |
| Does the intervention program provide an integrated educational program for children who are interactive and can imitate, as well as daily peer play? | <input type="checkbox"/> | <input type="checkbox"/> |
| Does the intervention program provide biomedical approaches based on the child's individual differences? | <input type="checkbox"/> | <input type="checkbox"/> |
| Does the intervention program provide access to appropriate technology-based learning? | <input type="checkbox"/> | <input type="checkbox"/> |
| Are consultations by a developmental or mental health specialist available to help construct and monitor the program and work on the three types of learning interactions and on family patterns? | <input type="checkbox"/> | <input type="checkbox"/> |
| Does the intervention program begin immediately after problems are assessed? | <input type="checkbox"/> | <input type="checkbox"/> |
| Do the same therapist and teacher(s) work with the child and family throughout infancy and early childhood, without a disruptive change when the child reaches age 3? | <input type="checkbox"/> | <input type="checkbox"/> |

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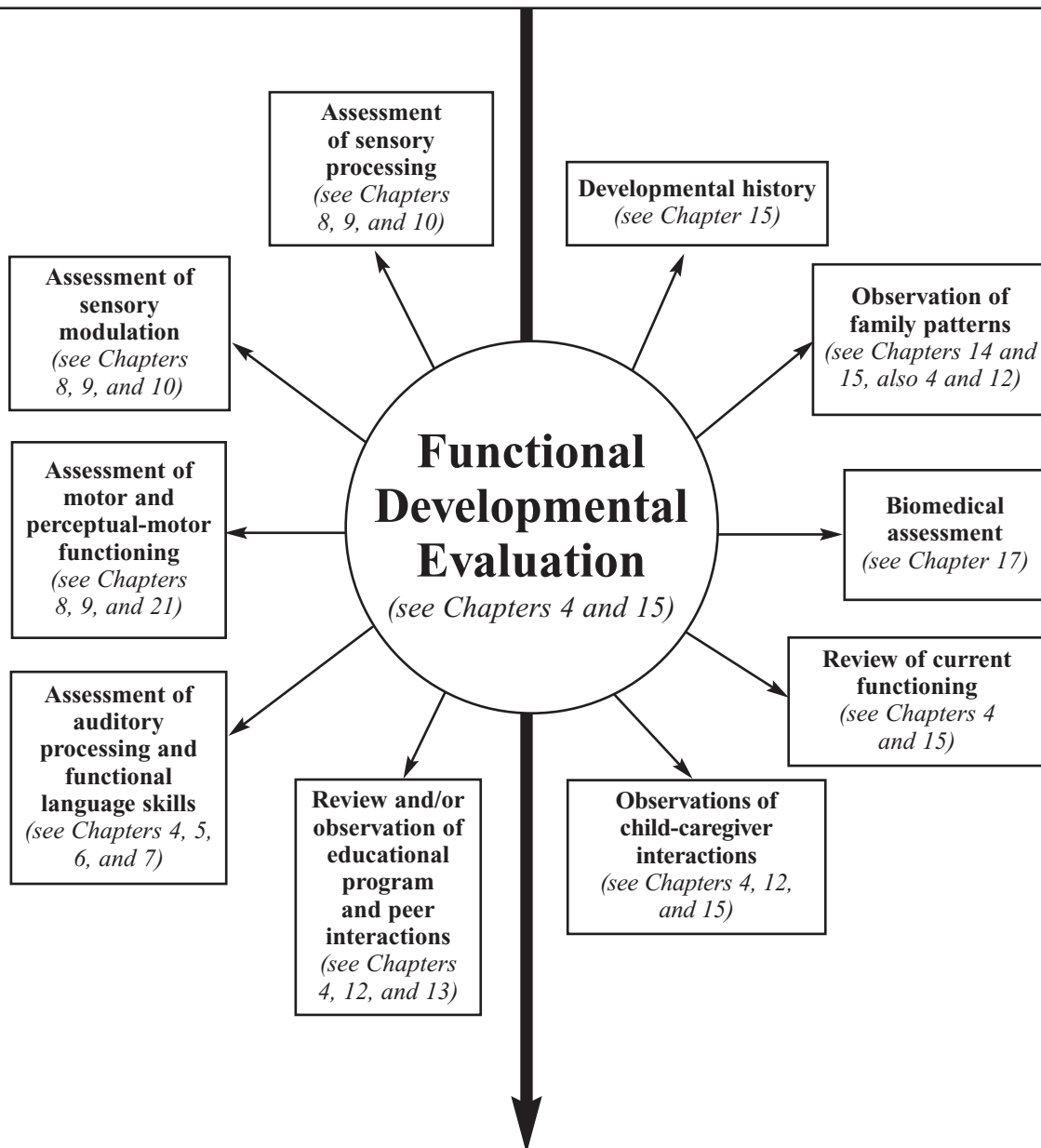
Appendix A

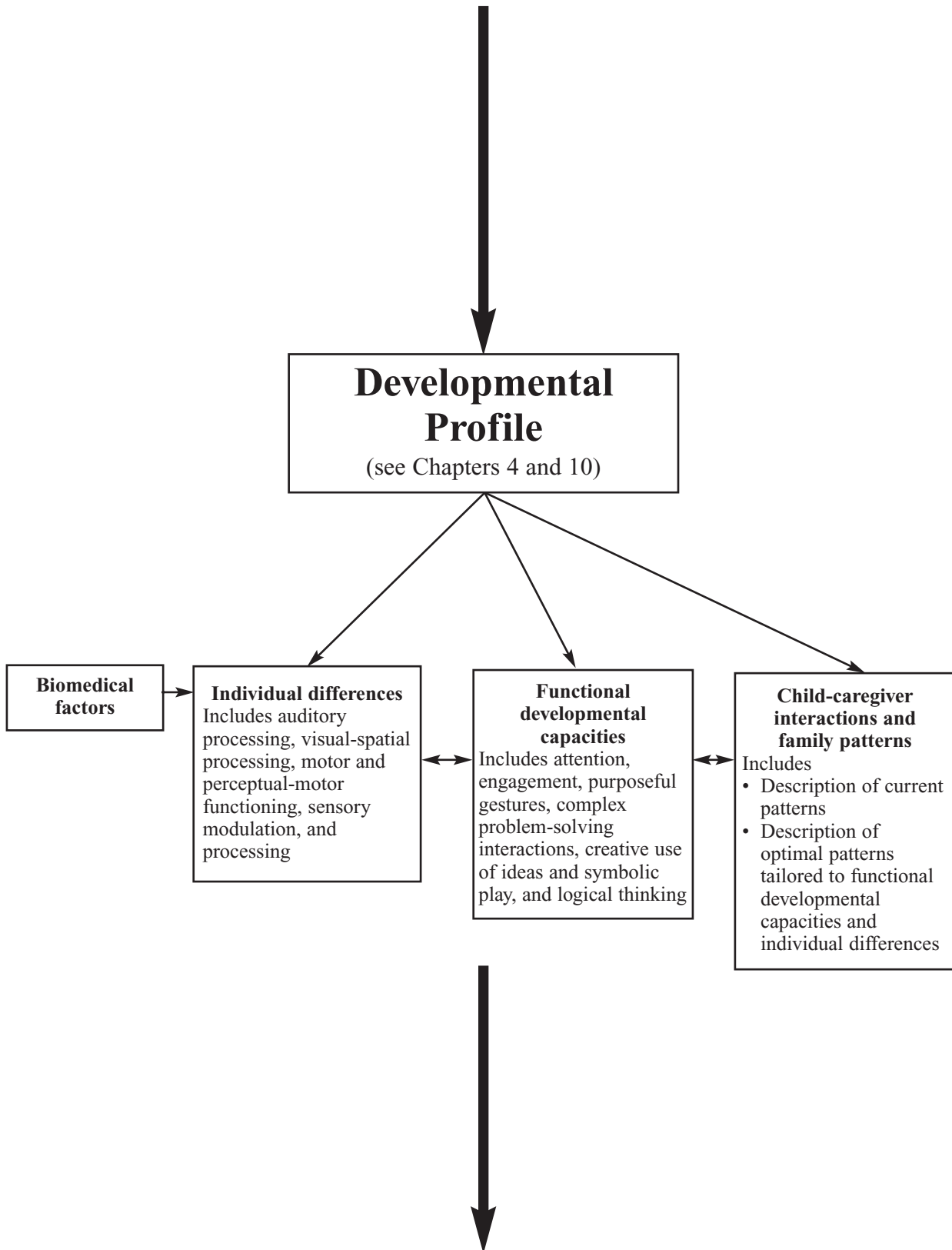
OUTLINE OF THE DIR MODEL

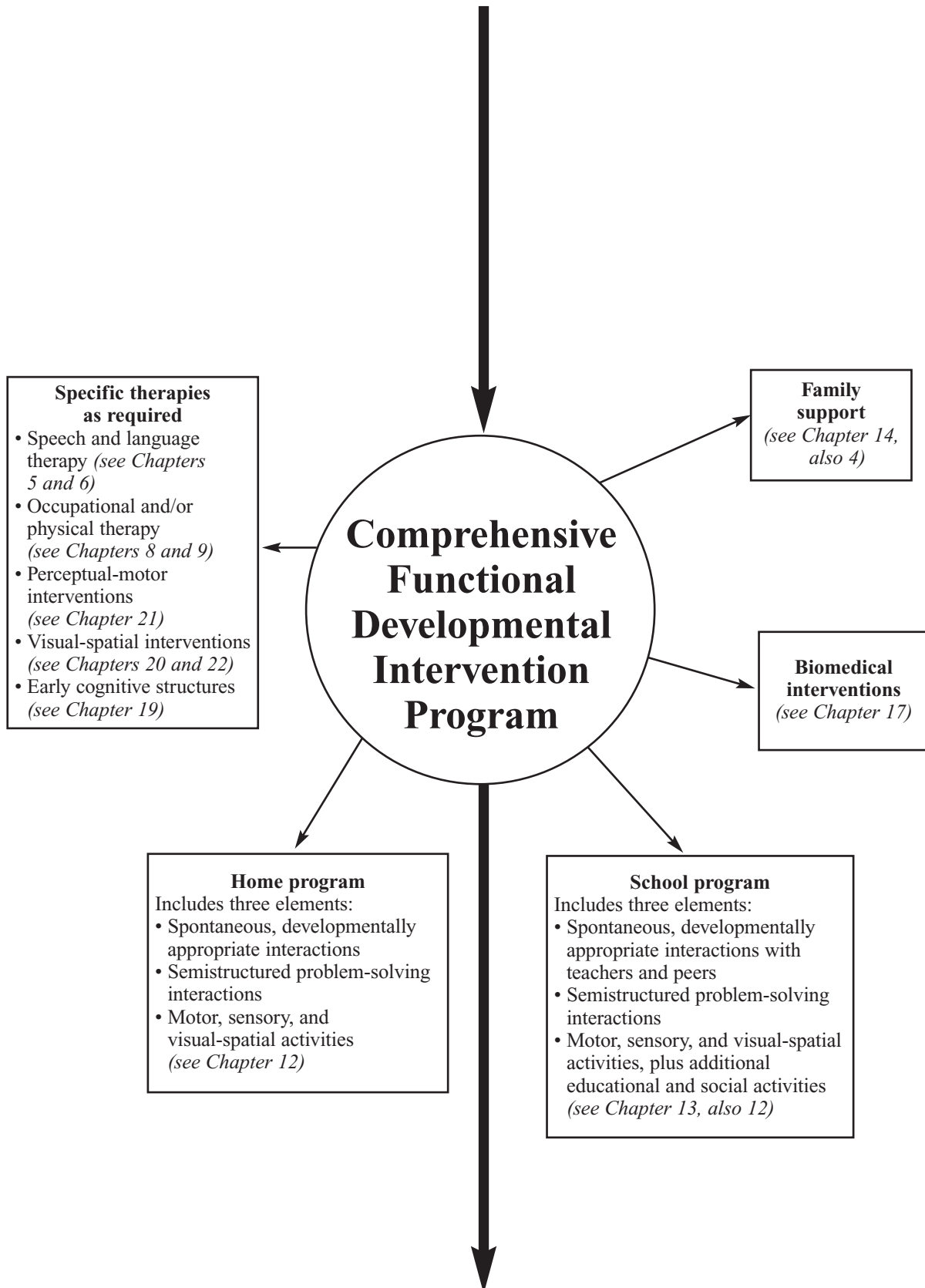
How to Use *The ICDL Clinical Practice Guidelines*

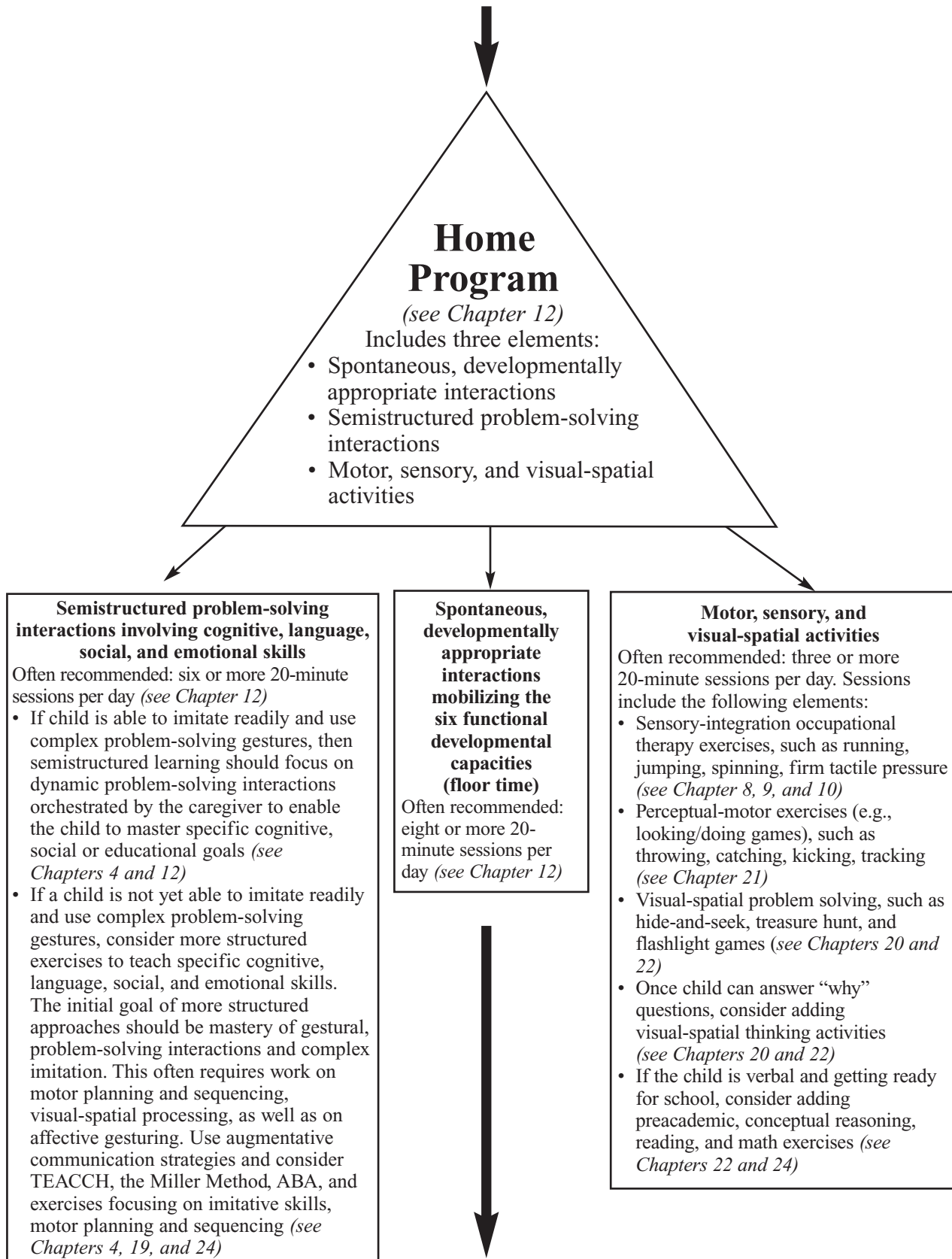
Screening (Functional Developmental Growth Chart)

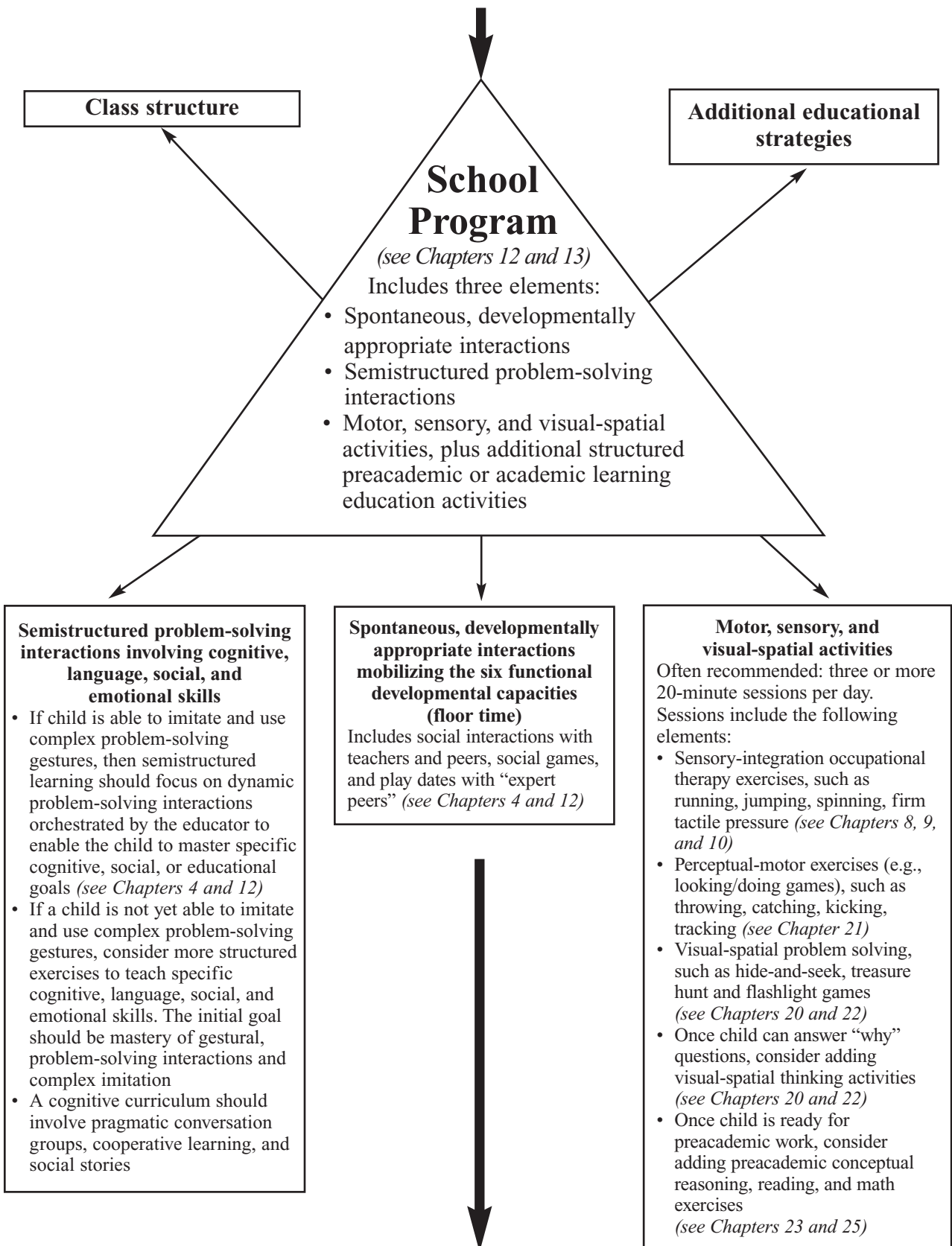
If at any time during the early years, a child experiences a loss or lack of progress in developing long chains of emotional cueing—regardless of other symptoms—proceed to a **full, functional developmental evaluation**. Most commonly, the loss or lack of progress in developing a continuous flow of reciprocal emotional cueing is seen between 8 and 18 months of age. (See the *Functional Developmental Growth Chart* (Chapter 3, Appendix B).

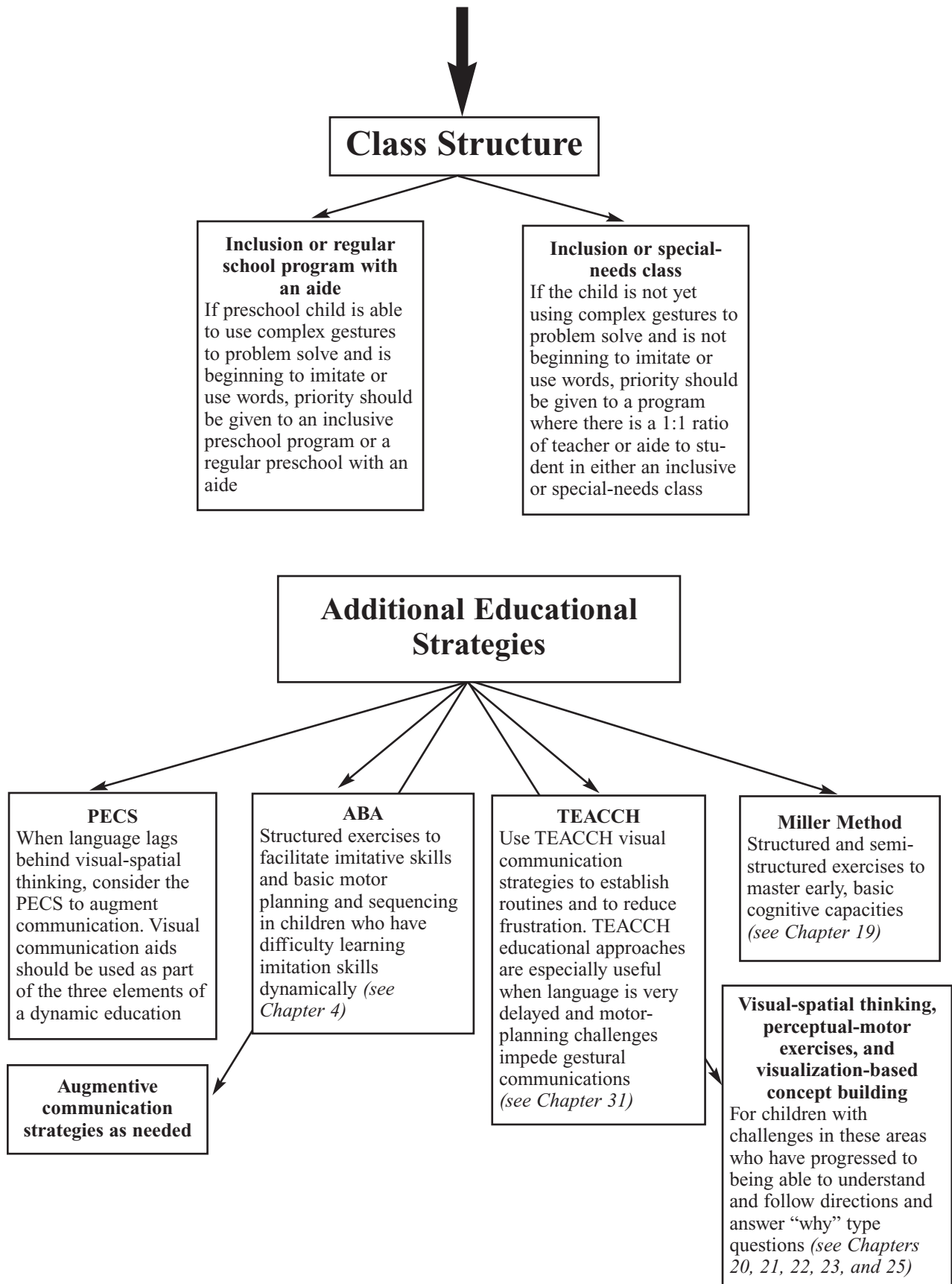












Appendix B

MONITORING DEVELOPMENT, PREVENTION, AND EARLY INTERVENTION:

The Functional Developmental Growth Chart and Questionnaire

Stanley I. Greenspan, M.D.

One of the most important components of a functional approach to intervention is for clinicians to initiate the interventions at the earliest possible time. Early intervention minimizes a child's ongoing functional impairments and missed opportunities for mastering critical functional developmental skills. For example, many children who are diagnosed between ages 2½ and 4 with autistic spectrum disorders began evidencing a subtle deficit in affective reciprocity and complex, preverbal, interactive problem-solving patterns between 12 and 16 months of age (Greenspan & Wieder, 1997) and by 18 months of age often are unable to engage in joint attention tasks, purposeful pointing, and early forms of pretend play (Baron-Cohen, Frith, & Leslie, 1988). The children who are not helped to learn how to engage in complex, social problem-solving interactions at this age (e.g., leading Daddy by the hand to the toy area and pointing to the desired play object) miss an opportunity for mastering critical social, emotional, language, and cognitive milestones that build on these problem-solving interactions during the second year of life.

There is mounting evidence that the absence of critical functional developmental capacities is associated with increased likelihood of severe developmental disorders. For example, in studies of autistic spectrum and related developmental disorders, the following capacities are often not present: joint attention (Mundy, Sigman, & Kasari, 1990),

social reciprocity (Baranek, 1999; Dawson & Galpert, 1990; Lewy & Dawson, 1992; Osterling & Dawson, 1994; Tanguay, 1999; Tanguay, Robertson, & Derrick, 1998;), functional language (Wetherby & Prizant, 1992), selected early motor capacities (Teitelbaum & Teitelbaum, 1999), motor-planning and sequencing capacities (Williamson & Anzalone, 1997), and early indications of symbolic functioning (e.g., pretend play, empathy) (Baron-Cohen, 1999; Baron-Cohen et al., 1988).

There is a confluence of studies showing the presence of certain milestones in healthy development and their absence in children at risk for or evidencing disorders of relating, thinking, and communicating. These studies, together with the growing road map of social, emotional, cognitive, language, and motor milestones, provide the basis for delineating essential functional developmental landmarks (Greenspan, 1992; Greenspan & Lourie, 1981). Therefore, just as a child's physical growth can be charted, the progression of functional developmental capacities should be monitored to help identify difficulties and strengths at the earliest possible age.

There are three levels to monitoring a child's functional developmental capacities. The first level involves broadening and updating the frame of reference pediatricians and other primary health care professionals, educators, and parents use for clinical observations and/or questions about an infant and

young child's development. This involves using the functional developmental milestones outlined earlier and in the Functional Developmental Growth Chart and the Questionnaire that follow. These milestones incorporate the well-known motor, language, social, and cognitive landmarks such as crawling, walking, first sounds and words, smiling, and imitating, as well as developmental indicators described by the Child Neurology Society of the American Academy of Neurology as being "nearly universally present by the age indicated" (no babbling by 12 months; no gesturing, pointing, or waving "bye-bye" by 12 months; no single words by 16 months; no two-word spontaneous (e.g., functional) phrases by 24 months; and any loss of language or social skills at any age) (Fillipek et al., 1999). The functional developmental milestones, however, go beyond these well-known indicators and focus on integrated functional developmental capacities identified in more recent studies and clinical observations (Greenspan 1992, 1997; Greenspan & Wieder, 1998, 1999).

Historically, clinicians have approached children's development in terms of isolated areas, such as motor development, the functioning of the senses, aspects of language and cognition, spatial problem solving, and social functioning. When looking at separate areas of development, a child can operate at a relatively advanced level in one area (e.g., motor development), and yet have significant challenges in another area (e.g., language development). Although specific aspects of development are very important to identify and assess, it is more useful for monitoring purposes to look at the full range of a child's functional developmental capacities and the way in which the child uses all her abilities together.

The child's functional, emotional developmental capacities require a coming together of the child's motor skills and her sensory

processing, cognitive, and language capacities, under the guidance of her emotional intent and proclivities. These functional emotional developmental capacities include the child's ability to focus and attend, engage with others, initiate reciprocal interactions to intentionally communicate needs (such as reaching to be picked up), and move on to complex problem-solving interactions (such as taking the caregiver by the hand to find the desired toy). They also include the child's ability to use ideas and words to communicate basic needs, as well as to explore imaginative thinking (make-believe) and to use logical bridges to combine ideas as a basis for rational thinking, advanced logical communication, and symbolic problem solving.

Each of these functional developmental capacities has an emotional, language, motor, sensory, and cognitive component. For example, the capacity for back-and-forth interaction (reciprocity) has a social and emotional component (the child's desire or intent to communicate, get a toy, or smile), a motor component (purposeful smiles or hand movements), a language component (using sounds for communicative intent), a sensory component (visual and auditory processing and responding to the gestures of the other person), and a cognitive component (engaging in "means/ends" [i.e., purposeful] interactions). The clinician, however, does not need to consider all the separate components or all possible examples of a particular milestone. He needs only to ascertain through a simple question or observation if the milestone is present or absent; for example, if a 9-month-old infant can initiate and respond to purposeful actions. Each of these readily identifiable milestones (no more difficult to ascertain than a child's ability to walk) can be easily asked about and/or observed. For example, a simple question or observation

could elicit the presence or absence of this back-and-forth interaction.

When a child is unable to master these functional developmental milestones, different components of development might be contributing to the child's difficulty. Simply having a mild motor delay, for example, may not derail relating, communicating, or thinking. On the other hand, a mild motor delay coupled with severe family dysfunction or a very severe motor delay might derail one or more functional developmental milestones. The functional developmental milestones are the common pathways or the doors through which the child navigates. The child's ability or inability to walk through these doors provides an important picture of his adaptive and maladaptive development and the need for further evaluation and, possibly, intervention.

If observing and/or asking about a child's functional developmental capacities raises questions about appropriate progress, a second level of monitoring should be considered. This should involve screening questionnaires which have been used with a large number of children and shown to identify different types of developmental problems. Screening questionnaires that cover a broad range of developmental competence include the Communication and Symbolic Behavior Scales Developmental Profile (Wetherby & Prizant, 1998) and the Ages and Stages Questionnaire (ASQ), A Parent-Completed, Child-Monitoring System, Second Edition (Bricker & Squires, 1999).

If a systematic screening questionnaire supports the impression from clinical observations and questions, then a third level should be considered—a comprehensive developmental evaluation to determine the nature and extent of a suspected problem (see Greenspan & Wieder, Chapters 4 and 15, this volume).

In order to broaden the frame of reference and implement the first level of monitoring an infant or child's progress, it may prove

helpful to have a functional developmental growth chart and questionnaire that identifies the milestones to be observed or asked about. The growth chart and screening questionnaire must provide straightforward, clear descriptions that can readily be observed by parents, health care providers, and educators. It must cover all the areas of developmental functioning—emotional, social, cognitive, language, motor, and sensory in an integrated manner—and all the stages of infancy and early childhood.

Figure B1 presents a functional developmental growth chart (followed by a functional developmental screening questionnaire) that is similar to a physical growth chart. The Functional Developmental Growth Chart enables clinicians to look at the pattern of a child's growth rather than simply at a few items at a certain age. Patterns of change over time often provide the most useful information about a child's abilities.

In Figure B1, the functional developmental capacities to be monitored are listed on the horizontal axis. The child's age is on the vertical axis. A 45-degree line shows the expected age range at which a child is expected to master each capacity. As can be observed on the chart, the child's functional developmental accomplishments can be charted in relation to the age at which the accomplishment is expected to emerge and the age at which it does emerge. When a child does not evidence the next milestone during the expected time interval, the last functional capacity mastered is recorded on the chart. The next milestone, if it occurs, is then recorded at whatever later time it is manifested. The 45-degree line indicates a typical developmental curve. A child who is precocious in a predictable manner (e.g., 3 months ahead of expectations) will have a functional developmental curve that parallels the typical one and is a little above it. A child who is a

little behind the expected curve (e.g., 3 months behind on the functional developmental milestones) will have a curve that parallels the typical curve but may fall just below it. When a child's curve is below the norm, the child should be evaluated to identify which factors may be contributing to the developmental lag and what may be helpful in responding to them.

Most worrisome, and a red flag, is a curve that arcs away from the line, that is, the distance from that line keeps growing, indicating a delay that is increasing as the child becomes older (shown as the lowest line on the chart). At the point the curve begins arcing is the point at which immediate assessment and possible intervention is indicated. It is also a red flag if the developmental curve is running parallel to the typical curve but is significantly below it.

Some children master these milestones a little bit later than expected but, as time goes on, they move closer to the expected functional developmental curve. Other children, however, may begin on the expected curve but gradually slip behind. The key is to watch

the child's pattern over time and, if for example, the child is slipping further behind, even if it is not dramatic, a full screening and possible evaluation is usually indicated.

The age expectations for each milestone are deliberately set up at the outer boundaries of the expectable range for that capacity to allow for a great deal of individual variation.

This developmental chart can be used by parents, educators (including daycare staff), and other childcare facilitators to monitor a child's functional developmental capacities. In general, a child will have mastered the milestone when she can engage in the behavior associated with the milestone most of the time. Mastery is not indicated in a child who only occasionally is able to mobilize the age-appropriate milestone or requires extraordinary support to perform it. The Functional Developmental Growth Chart Questionnaire follows the chart and provides questions that can be asked to parents or which parents can ask of themselves. These questions can help in determining the child's functional developmental level. ■

Functional Developmental Growth Chart Questionnaire

The purpose of this questionnaire is to assess whether a child has achieved a new functional developmental milestone. The child has mastered a milestone if the answer is “yes” to all the questions under that milestone. If the answer is “no” to even one question, the child has not yet mastered the milestone. Remember, the growth chart is simply a visual tool to draw attention to those developmental areas where a child is progressing as expected and those where he or she may be facing some challenges.

By 3 Months (Stage 1- Focusing and Attention)

- Does your infant usually show an interest in things around him/her by looking at sights and turning towards sounds?

By 5 Months (Stage 2 - Engaging in Relationships)

(Ask the question from the prior category plus the new one from this category.)

- Does your baby seem happy or pleased to see you and/or other favorite people: looking and smiling, making sounds or some other gesture, such as moving arms, that indicates pleasure or delight?

By 9 Months (Stage 3 - Interacts in a Purposeful Manner)

(Ask the questions from all prior categories plus the new ones from this category.)

- Is your baby able to show what he/she wants by reaching for or pointing at something, reaching out to be picked up, or making purposeful special noises?
- Does your baby respond to people talking or playing with him/her by, for example, making sounds, faces, or initiating gestures (reaching)?

By 14 to 18 Months (Stage 4 - Organizes Chains of Interaction; Problem Solving)

(Ask the questions from all prior categories plus the new ones for this category.)

- Is your toddler (by 14 months) able to show what he/she wants or needs by using actions, such as leading you by the hand to open a door or pointing to find a toy?
- Is your toddler (by 18 months) able to orchestrate more complex chains of interaction as he/she solves problems and shows you what he/she wants, including such things as getting food. For example, does he/she take your hand, lead you to the refrigerator, tug on the handle, and point to a particular food or bottle of juice or milk?
- Is your toddler (by 18 months) able to use imitation, such as copying your sounds, words, or motor gestures, as part of a playful, ongoing interaction?

**By 24 to 30 Months (Stage 5 - Uses Ideas—Words or Symbols—
to Convey Intentions or Feelings)**

(Ask the questions from all prior categories plus the new ones for this category.)

- Does your toddler (by 24 months) ever respond to people talking with or playing with him/her by using words or sequences of sounds that are clearly an attempt to convey a word?
- Is your toddler (by 24 months) able to imitate familiar pretend-like actions, such as feeding or hugging a doll?
- Is your toddler (by 24 months) able to meet some basic needs with one or a few words, such as “juice,” “open,” or “kiss”? (A parent may have to say the word first.)
- Is your toddler (by 24 months) able to follow simple one-step directions from a caregiver to meet some basic need, for example, “The toy is there,” or “Come give Mommy a kiss.”
- Is your toddler (by 30 months) able to engage in interactive pretend play with an adult or another child (feeding dollies, tea parties, etc.)?
- Is your toddler (by 30 months) able to use ideas—words or symbols—to share his/her delight or interest (“See truck!”)?
- Is your toddler able to use symbols—words, pictures, organized games—while enjoying and interacting with one or more peers?

By 36 to 48 Months (Stage 6 - Creates Logical Bridges Between Ideas)

(Ask the questions from all prior categories plus the new ones for this category.)

- Is your toddler (by 36 months) able to use words or other symbols (for example, pictures) to convey likes or dislikes, such as “want that” or “no want that”?
- Is your toddler (by 36 months) able to engage in pretend play with another person in which the story or drama makes sense? (e.g., in the story, do the bears go visit grandmother and then have a big lunch)?
- Is your toddler (by 36 months) able to begin to explain wishes or needs. For example, a conversation may contain an exchange such as: “Mommy, go out.” “What are you going to do outside?” “Play.” The child may need multiple choice help from the parent, such as “What will you do, play or sleep?”
- Can your preschooler (by 48 months) explain reasons for wanting something or wanting to do something (e.g., “Why do you want the juice?”...“Because I’m thirsty”)?
- Is your preschooler (by 48 months) occasionally able to use feelings as a reason for a wish or behavior (e.g., “I don’t want to do that because it makes me sad”)?
- Is your preschooler (by 48 months) able to engage in interactive pretend dramas with both peers as well as adults in which there are a number of elements that logically fit together (e.g., the children go to school, do work, have lunch, and meet an elephant on the way home)?
- Is your preschooler (by 48 months) able to engage in a logical conversation with four or more give-and-take sequences about a variety of topics, ranging from negotiating foods and bed-times to talking about friends or school?

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◀ 4 ▶

Principles of Clinical Practice for Assessment and Intervention

Stanley I. Greenspan, M.D., and Serena Wieder, Ph.D.

The discussion in Chapter 2 states that developmental and learning disorders involve varying degrees of impairment in critical central nervous system (CNS) functions, such as motor capacities, language, cognition, sensory, and social and emotional functioning. This chapter continues the discussion by describing the functional developmental approach and its relationship to general principles of clinical practice.

THE FUNCTIONAL DEVELOPMENTAL APPROACH

Most non-progressive developmental and learning disorders, including disorders of relating and communicating (e.g., autistic spectrum or pervasive developmental disorders [PDD], multisystem developmental disorders, severe language and cognitive deficits) are nonspecific with regard to their etiology and pathophysiology. Non-progressive developmental disorders are, therefore, best characterized by types and degrees of functional limitations and processing differences as well as by symptoms that often are only one expression of a functional limitation (e.g., echolalia is a symptom; pragmatic language is the functional limitation).

Yet, as indicated in Chapters 2 and 3, both historically and recently, clinicians have

focused on symptoms and groups of symptoms comprising syndromes, giving only partial attention to a broad range of important functional capacities and their related processing differences. For example, a mother was told by the senior clinician overseeing an evaluation team that because her child was “autistic,” he could not interact with purpose and meaning. The clinician concluded that, because an intensive intervention would not be helpful, the therapeutic effort should be modest. Yet, this clinician did not assess the relative strengths and weaknesses of all the child’s areas of functioning and underlying processing capacities to see which ones required work and which ones could be harnessed immediately for interacting and learning. For example, was this child’s lack of purposeful interaction related to auditory processing and motor problems? Did he have some relative strengths in visual-spatial processing that could be partially harnessed to enable him to interact with others more purposefully? Would working with him on activities that were associated with high motivation (e.g., his eagerness to go outside) help him become more purposeful? Or, was his lack of purposeful interaction part of a biologically based CNS impairment which, by definition, would remain chronic and relatively untreatable?

Cases such as this one suggest the importance of looking at functional capacities. In fact, there is mounting evidence that:

1. Most complex, non-progressive developmental and learning disorders involve processing dysfunctions, each with its own natural history and complex, poorly understood etiology and neurobiology (see Zimmerman & Gordon, Chapter 27, and Minshew & Goldstein, Chapter, 28, this volume).
2. Key functional capacities, as well as related symptoms, learning problems, adaptive capacities, and a variety of surface behaviors, in turn, are often the result of the interaction between early and ongoing interactive experiences and these biologically based processing dysfunctions.
3. The resulting functional capacities, symptoms, or behaviors are not tied to these underlying processes in a rigid, fixed manner. For example, a child who cannot use words to symbolize a wish for juice may be able to learn to use a sign or a picture to symbolize her wish, suggesting many alternatives to symbolization.

Observed behavior, therefore, is often the result of dynamic interactions between the environment and genetic, prenatal, perinatal, and maturational variations. For example, genetic expression is influenced by a number of cellular and extracellular biological processes, including different hormones and toxic substances. Resultant physiologic levels are modified by different levels of interaction with the physical, cognitive, and social environment. Resultant functional capacities and behaviors are further influenced by interactions with different aspects of the environment. (These processes, which can be systematically described in terms of Biomedical traits, Original traits, Learned coping mechanisms, and Derived behaviors [BOLD] are more fully

discussed by Rosenbloom, Chapter 30, this volume).

Many practitioners, especially those in speech and language pathology, occupational therapy, physical therapy, education, and psychology have been expanding a dynamic functional approach that takes into account the dynamic relationship between behavior and the CNS. These practitioners are demonstrating that interactions geared to individual differences can facilitate important functional capacities such as relating, thinking, and communicating.

For example, motor-planning (including oral-motor) exercises can help develop a child's preverbal vocal, motor, and affective gesturing, imitation, and language development. Visual-spatial, problem-solving approaches can aid logical thinking and abstract academic challenges. Sensory modulation work can help a child learn to relate to others and with receptive language, whereas auditory discrimination work can facilitate the child's phonemic awareness as a basis for reading.

In spite of an expanding functional approach, however, many clinicians continue to focus predominantly on symptoms and only a few of the functional areas (e.g., more on verbal development and less on intimacy, relating, and preverbal affective gesturing). Similarly, there is a tendency to focus only on a few of the critical underlying processing differences. For example, some clinicians focus more on auditory processing and less on motor planning and sequencing, which is essential for imitation, social interaction, play, and language. Others may focus more on rote cognitive and social skills and less on spontaneous interaction to promote affective processing.) (See Tsakiris, Chapter 31, this volume).

Consequently, it is important to further systematize and expand a functional approach. In this approach, assessments and interventions must include the contributions

of all relevant areas of functioning, processing differences, and interactive relationships (see Chapter 2). Chart 1 summarizes the relevant areas.

THE FUNCTIONAL DEVELOPMENTAL APPROACH TO ASSESSMENT

Implementing an appropriate assessment of all the relevant functional areas requires a

number of sessions with the child and family. These sessions must begin with discussions and observations. Structured tests, if indicated, should be administered later to further understand specific functional areas. The sessions should include:

- *Review of current functioning* with parents and other caregivers, looking at both problems and adaptive capacities.

Chart 1. Relevant Areas to Consider in a Functional Developmental Approach

The functional developmental level of the child's communicative, cognitive, and emotional capacities (i.e., how the child integrates all his capacities to meet emotionally meaningful goals, such as using a continuous flow of social problem-solving gestures to get Daddy to reach for and get him a desired toy).

Includes:

1. Shared attention and regulation
2. Engagement
3. Purposeful preverbal/gestural and affective communication
4. Complex social problem-solving interactions
5. The creative and meaningful use of ideas
6. Building logical connections between ideas or symbols (Greenspan, 1992)

Individual differences in the functioning of the child's motor, sensory, and affective patterns

Includes:

1. Sensory modulation (e.g., the degree to which the child is over- or underreactive to sensations in each sensory modality such as touch, movement, sound, sight)
2. Auditory and visual-spatial processing
3. Motor planning and sequencing and affective processing (i.e., the connection between affect, motor planning, other processing capacities, and emerging symbols)

Relationship and affective interaction patterns, including developmentally appropriate interactions (which utilize understanding of the child's functional developmental level and individual differences) or inappropriate interactions

Includes:

1. Existing caregiver, parent, family patterns
2. Educational patterns
3. Peer patterns

- *Review of prenatal, perinatal, and postnatal developmental history*, including development in all the functional areas.
 - *Observations of child-caregiver interactions* for 45 or more minutes, including “coaching” or interactions with the clinician to elicit the child’s highest adaptive level. There should be at least two observation sessions, with additional sessions scheduled if there is a discrepancy between parental reports and observed functioning. These sessions should serve, together with a history and review of current functioning, as a partial basis for a preliminary impression of the child’s functional developmental capacities and individual processing differences, including those that are often underemphasized, such as motor planning, visual-spatial processing and affective processing, and current as well as potentially optimal child-caregiver interaction patterns.
 - *Discussion of caregiver personality patterns and child-caregiver interactions*, including identification of strengths and vulnerabilities as well as family and cultural patterns.
 - *Review of all current interventions, educational programs, daily activities, behaviors, and interaction patterns*. There should be review and consideration of developmentally appropriate interaction patterns and practices at home, in school, with peers, and in different interventions in regard to their capacity to foster the next level in the child’s functional abilities.
 - *Review and assessment to rule out (or identify) concurrent and/or contributing medical disorders*. This includes conducting appropriate biomedical assessments to identify biological interventions that may contribute to clinical management (e.g., a 24-hour EEG may reveal the potential usefulness of Depakote or other antiseizure medications). (See Robinson, Chapter 17, this volume).
 - *Additional developmental and learning assessments*, such as speech and language functioning, motor and sensory functioning, and specific aspects of cognitive functioning, should be conducted as needed (as opposed to routinely) to answer specific questions. For example, a child with a circumscribed receptive language difficulty may benefit from structured language assessments to tease out more precisely the nature of the deficit. A child with a circumscribed learning problem may benefit from specific structured tasks to tease out areas of strength and weakness, such as visual-spatial processing or motor planning (e.g., a neuropsychological battery). Specific assessments, however, must always build on a basic evaluation because even circumscribed processing difficulties often make it more difficult for a child to process and understand important functions of social relationships. Therefore, the processing difficulties may be associated with emotional, behavioral, and/or family challenges.
- In contrast, a child who is only fleetingly engaged or aimless and has receptive as well as expressive language problems may be best understood through ongoing interactive observation and the child’s response to a comprehensive intervention program. Such a child may not be able to fully cooperate in a structured developmental assessment and even the best evaluator may only be able to describe the child’s behavior in the assessment situation. In such circumstances, clinical observation of caregiver- and clinician-child interactions to observe functional capacities coupled with a review of current and past functioning provide an initial picture of strengths and challenges. Further profiling

may then best done as part of the intervention process. (See Gerber & Prizant, Chapter 5; Long & Sippel, Chapter 9; Greenspan & Wieder, Chapter 12, this volume.)

THE FUNCTIONAL PROFILE

The functional assessment leads to an individualized functional profile that captures each child's unique developmental features and serves as a basis for creating individually tailored intervention programs. The profile describes the child's functional developmental capacities, contributing biological processing differences, and environmental interactive patterns, including the different interaction patterns available to the child at home and at school, with peers, and in other settings. The profile should include all areas of functioning, not simply the ones that are more obviously associated with pathologic symptoms. For example, a preschooler's lack of ability to symbolize a broad range of emotional interests and themes in either pretend play or talk is just as important, if not more important, than that same preschooler's tendency to be perseverative or self-stimulatory. In fact, clinicians have often seen that as the child's range of symbolic expression broadens, perseverative and self-stimulatory tendencies decrease. Similarly, a child's areas of special strength may also be critical to the intervention program. For example, visual-spatial thinking capacities may enable a child with severe language problems to interact with others, learn, and reason.

Because the functional profile captures each child's individual variations, children with the same diagnosis (e.g., PDD) may have very different profiles, whereas children with different diagnoses may have similar profiles. The functional profile is updated continually through clinical observations, which serve as a basis for revising the child's intervention program.

The Affect Diathesis Hypothesis

Looking at children with autistic spectrum disorders within the context of their functional profiles highlights a number of important findings. These findings provide clues regarding a core psychological mechanism that may express the neurological differences characterizing autistic spectrum disorders. When children with autism are compared to children without autism, and level of intelligence as measured with IQ tests is controlled for, there are a number of autism-specific functional deficits. These include deficits in the ability for empathy (theory of mind) (Baron-Cohen, 1994); higher-level abstract thinking and skills in making inferences (Minschew & Goldstein, 1998); and shared attention, including social referencing and problem solving (Mundy, Sigman, & Kasari, 1990). In addition, deficits in the capacities for affective reciprocity (Baranek, 1999; Dawson & Galpert, 1990; Lewy & Dawson, 1992; Osterling & Dawson, 1994; Tanguay, 1999; Tanguay, Robertson, & Derrick, 1998), and functional (pragmatic) language (Wetherby & Prizant, 1993) also appear specific to autism.

These functional deficits have a feature in common that may suggest an overriding or core psychological deficit. Clinical work with infants and children without challenges and those with biological challenges and environmental challenges demonstrates that the capacities for empathy, psychological mindedness, abstract thinking, social problem solving, functional language, and reciprocity all stem from the infant's ability to connect affect or intent to motor-planning capacities and emerging symbols (Greenspan, 1979, 1989, 1997). Relative deficits in this core capacity lead to problems in these higher-level emotional and intellectual processes.

A child's capacity to connect affect to motor planning and emerging symbols

becomes relatively apparent between 9 and 18 months of age as the infant shifts from simple patterns of engagement and reciprocity to complex chains of affective reciprocity that involve problem-solving interactions. Consider a 14-month-old child who takes his father by the hand and pulls him to the toy area, points to the shelf, and motions for a toy. After Dad picks him up, he nods, smiles, and bubbles with pleasure. For this complex, problem-solving social interaction to occur, the infant needs to have a wish, desire, or intent (i.e., inner affects or emotions) that indicate what he wants. The infant then needs an action plan (i.e., a plan to get his toy) that may involve many steps. However, the direction-giving affects must connect to the action plan in order for the child to create a pattern of meaningful, social problem-solving interactions. Without this connection between affect and action plans (i.e., motor planning), complex interactive problem-solving patterns are not possible. Action plans without affective direction or meaning will tend to become repetitive (perseverative), aimless, or self-stimulatory, which is what is observed when there is a deficit in this core capacity.

As the ability to form symbols emerges, inner affects (intent) need to connect to symbols to create meaningful ideas, such as those involved in functional language, imagination, and creative and logical thought. The meaningful use of symbols usually emerges from meaningful (affect-mediated) problem-solving interactions that enable a toddler to understand the patterns in her world and eventually use symbols to convey these patterns in thought and dialogue. Without affective connections, symbols such as action plans will be used in a repetitive (perseverative) manner (e.g., scripting, echolalia).

Affectively guided problem-solving interactions and symbols are necessary for all the unique capacities that distinguish individuals

with autism from individuals without autism, as outlined earlier. For example, long chains of social reciprocity depend on affect guiding interactive social behavior. Shared attention, which includes social referencing and shared problem solving, also depends on affect guiding interactive social behavior. Empathy and theory of mind capacities depend on the ability to understand both one's own affects or feelings and another person's affects or feelings, and to project oneself into the other person's mindset. This complex emotional and cognitive task begins with the ability to exchange affect signals with another person and, through these exchanges, emotionally sense one's own intent and sense of self in interaction with another. Similarly, higher-level abstract thinking skills, such as making inferences, depend on the ability to generate new ideas from one's own affective experiences with the world and then reflect on and categorize them (Greenspan, 1997).

In observations of infants and toddlers heading into autistic patterns and in taking careful histories of older children with autism, we have noted that children with autistic spectrum patterns did not fully make the transition from simple patterns of engagement and interaction into complex affect-mediated, social problem-solving interactions. They, by and large, did not progress to a continuous flow of affective problem-solving interchanges. Even affectionate children who were repeating a few words or memorizing numbers and letters, and who went on to evidence autistic patterns, did not master, for the most part, this early capacity to engage in a continuous flow of affect-mediated, gestural interactions. These children were then unable to develop higher-level capacities for empathy and creative and abstract thinking unless an intervention was initiated that focused on facilitating affect-mediated interactions.

In a review of the functional profiles of 200 cases of children with autistic spectrum

disorders, we observed that most of the children shared this unique processing deficit. At the same time, the children differed with regard to other processing deficits involving their auditory, motor-planning, visual-spatial, and sensory modulation abilities. Approximately two-thirds of the children who developed autistic spectrum disorders had this unique type of biologically based processing deficit that involved the connection of affect or intent to motor planning and sequencing capacities as well as to emerging symbolic capacities (Greenspan and Wieder, 1997).

The hypothesis that explores this connection between affect and different processing capacities is called the *affect diathesis hypothesis*. In this hypothesis, as indicated previously, a child uses his affect to provide intent (i.e., direction) for his actions and meaning for his words. Typically, during the second year of life, a child begins to use his affect to guide intentional problem-solving behavior and, later on, meaningful use of language. Through many affective problem-solving interactions, the child develops complex social skills and higher-level emotional and intellectual capacities.

Because this unique processing deficit occurs early in life, it can undermine the toddler's capacity to engage in expectable learning interactions essential for many critical emotional and cognitive skills. For example, she may have more difficulty eliciting ordinary expectable interactions from her parents and the people in her immediate environment. Without appropriate interaction, she may not be able to comprehend the rules of complex social interactions or to develop a sense of self. A child normally develops these skills and capacities at an especially rapid rate between 12 and 24 months of age. By the time a child with processing difficulties receives professional attention, her challenging interaction patterns with her caregivers

may be intensifying her difficulties. She is likely to perplex, confuse, frustrate, and undermine purposeful, interactive communication with even very competent parents. This loss of engagement and intentional, interactive relatedness to key caregivers may cause a child to withdraw more idiosyncratically into her own world and become even more aimless and/or repetitive. What later looks like a primary biological deficit may, therefore, be part of a dynamic process through which the child's lack of interactions has intensified specific, early, biologically based processing problems and derailed critical social skills.

Biologically based processing (regulatory) difficulties, therefore, often contribute to, but are not decisive, in determining relationship and communication difficulties. When problems are perceived early, appropriate professional help can, to varying degrees, teach children and caregivers how to work with the processing (regulatory) dysfunctions, including helping the toddler connect affect to emerging action plans and their associated relationship and communication patterns. Such children can often become capable of forming warm relationships and climb the developmental ladder leading to language and thinking capacities.

There are many children who do not evidence autism but have developmental problems in which intentionality or purposeful action is difficult in its own right and results in less practice or use (e.g., severe motor problems). These children may either have difficulty forming or may secondarily lose their ability to connect intent or affect to motor planning. In these circumstances, creating purposeful interactions around any motor skill (e.g., head or tongue movements) may strengthen the affect-motor connection, reduce aimless, repetitive behavior, and facilitate problem solving and thinking. Recent

MRI studies suggest that practicing and improving motor skills may enhance the developmental plasticity of neuronal connections (Zimmerman & Gordon, Chapter 27, this volume).

In our review of 200 cases, we also found that, although many children with autistic spectrum disorders shared a primary deficit (i.e., connecting affect to processing capacities), they differed in the levels of developmental functioning of their different processing capacities or “component parts.” We noted that the relative strength of each component part tended to determine symptoms and splinter skills, such as whether a child lined up toys (which requires some motor planning) or just banged them, or scripted TV shows (which requires some auditory memory) or was silent. It was also found that children with relatively stronger component parts tended to make rapid progress once they were helped to connect affect or intent to their other processing capacities. Children with weaker component parts tended to make more gradual progress and required more intensive, specific therapies, such as speech and occupational therapy, in order to work with the component part directly.

These observations are consistent with recent neuroscience studies suggesting that different processing capacities may compete for cortical access, depending on functional use (Zimmerman & Gordon, Chapter 27, this volume). They are also consistent with neuropsychological studies of individuals with autism but without mental retardation that show that “within affected domains, impairments consistently involved the most complex tasks dependent on higher-order abilities (i.e., concept formation, complex memory, complex language, and complex motor abilities) (Minshew & Goldstein, 1998). Higher-level capacities tend to depend more on “meanings” which, in turn, depend on affective interactions with the world. Furthermore, these

observations are also consistent with work on the shifts to a more complex central nervous system organization, including hemispheric connections that occur at the end of the first year of life and early part of the second year, just as the ability to engage in affect-mediated chains of social problem solving are on the ascendancy (Benson & Zaidel, 1985; Courchesne et al., 1994; Dawson, Warrenburg, & Fuller, 1982; Sperry, 1985).

Dynamic Assessments over Time and in the Context of Interventions

The assessment of the functional processing and developmental capacities just described cannot be implemented based only on structured tests or a short observation. A child’s “functioning” involves her ability to learn over time and in contexts that provide learning opportunities. For example, observing how a child responds to interventions that foster engagement and interaction reveals more about the child’s relationship capacity than a one-time evaluation of how she relates to the clinician in an office. Similarly, the child’s ability to learn to gesture, imitate words, and use words purposefully is best assessed by observing her at home, in school, and in the clinician’s office when the child is highly motivated and provided with developmentally meaningful, interactive opportunities.

Traditional ways of assessing children with developmental problems, which include time-limited observations and structured tests, may often present a misleading picture because they do not deal with the child’s variability and range of functioning by looking at the child’s functioning in a dynamic learning situation over time. In fact, the use of structured tests raises an interesting paradox. Because many children with special needs are quite variable in their functioning, fixed (i.e., standard) presentations of stimuli,

which may appear attractive from a research point of view, are likely to produce a great deal of variability in functioning or bring out the child's lowest level of possible functioning. In contrast, optimal levels and stability of performance are enhanced by the flexibility of the presentation.

Criteria for Immediate Evaluation vs. "Wait and See"

A child with functional developmental impairments involving foundation-building capacities, such as relating and using gestures to communicate and problem solve, often requires *immediate* attention, not a "wait-and-see" attitude. Because functional capacities build on each other and there is mounting evidence of age and time limits to developmental, neurobiological plasticity in a child's brain, delaying evaluation can increase functional impairments. Delaying intervention until a child is 3 or 4 years old and evidences a clear syndrome tends to increase the therapeutic challenge and may affect the ultimate prognosis. As the child falls further and further behind, there are more missed opportunities. Therefore, a determination of developmentally significant functional impairment in and of itself should serve as a criterion for initiating an appropriate evaluation and intervention. This is especially true for functional impairments that derail the child's ability to attend, relate, communicate, play, or think. Because the functional impairments are the focus of the intervention, it is possible to begin the therapeutic work even while observing the child over time to determine an appropriate diagnosis. As new observations are made, the intervention program can be revised. In assessing functional impairments, distinctions must be made between circumscribed problems that do not derail the basics of relating, communicating,

and thinking and more substantial challenges that do derail them. For example, a toddler with a mild articulation problem who relates and communicates with purposeful gestures (e.g., takes Dad to the toy chest) has a circumscribed difficulty. This child is significantly different from a toddler who cannot use social gestures to show what he wants, even if he can repeat words and is being derailed in his fundamental ability to relate and communicate.

RETHINKING AUTISM, MENTAL RETARDATION, AND SEVERE ATTENTIONAL AND LEARNING PROBLEMS

Moving from standardized, one-time assessments to observing functional impairments in the context of truly helpful interventions over time will certainly change how therapists diagnose problems. It may, at times, change the ultimate diagnosis chosen for a child. These ongoing observations are especially relevant for autistic spectrum disorders, mental retardation, and many types of attentional and learning problems.

Autistic Spectrum Disorders

Some children who meet DSM-IV criteria for autistic spectrum disorders have responded very quickly to developmentally based, comprehensive intervention programs and become warmly related, interactive, and verbally communicative (Greenspan, 1992; Greenspan & Wieder, 1997, 1998). Within 1 year, for example, many of these children became engaged and interactive, overcoming their perseverative and self-stimulatory patterns. After 2 years of intervention, many used language flexibly and creatively, though still with delays. If the diagnosis of these children had been delayed for a year while

their response to intervention was observed, the diagnosis for this group of rapidly improving children would be language disorders and motor-planning problems, rather than the autistic spectrum disorders with which they initially presented. If diagnosis were delayed for 2 years, the diagnosis would be a less severe language disorder. Many of these children subsequently developed excellent language and learning abilities as well as a solid capacity to relate to others, including peers, with warmth, empathy, creativity, and a sense of humor. They often evidenced in their later school years more circumscribed processing problems involving motor planning and sequencing.

Other children who initially met the criteria for autistic spectrum diagnoses have made much slower progress: 1 and 2 years into the intervention, they continued to meet the criteria for autistic spectrum disorders, although with a greater capacity to relate and communicate. Still others have made extremely slow progress or no progress at all, continuing to meet the criteria for autism after many years.

Although each of these groups had a different presenting profile in terms of developmental capacities (e.g., relatedness, motor planning and sequencing, and visual-spatial processing), the most distinct difference among the groups is the way in which they have responded to an optimal intervention program. The response to intervention can further classify problems in relating and communicating. It raises a question of whether or not children who make extremely rapid progress and no longer meet DSM-IV criteria for PDD should be diagnosed as having an autistic spectrum disorder or a separate type of neurodevelopmental dysfunction. Should these children be diagnosed based on their initial presenting patterns or should therapists take into account their response to an intervention program, thereby leading to alternative diagnostic considerations? Further complicating the

diagnostic challenge is that many symptoms used by clinicians to diagnose autistic spectrum disorders, such as hand-flapping, repetitive behavior, and self-stimulation, are not specific to autism. These behaviors are also seen in children with severe motor-planning problems and sensory-modulation difficulties. Lack of relatedness and affective reciprocity is a more specific symptom, but it is often the first behavior to improve, especially in the children who respond quickly to treatment.

Mental Retardation

Because mental retardation implies relatively permanent cognitive deficits, observing the response to intervention may be even more important than with autistic spectrum disorders. Often, children who have a number of cognitive deficits are assessed as having relatively permanent global deficits and are diagnosed with varying degrees of mental retardation. Historically, intelligence tests (e.g., two standard deviations below the norm constitutes mild retardation) have been used to make this determination. This method, however, tends to look at the child only at one point in time and not take into account her learning curve over a longer period of time, which is essential for observing changes in her many functional capacities. Contrary to traditional expectations, many children who are diagnosed with mental retardation evidence different patterns of growth and, on close scrutiny, evidence relative strengths and weaknesses even if their intelligence subtest scores are all low.

The most accurate method for making a proper diagnosis is, therefore, to observe a child's progress while fostering her growth with a truly optimal program. If the child's learning curve levels off in spite of the best efforts of a comprehensive, intensive, intervention approach, it then might be reasonable

to conclude that the child has stopped making progress. Therefore, although cognitive problems should be noted and described, a diagnosis of mental retardation should only be given if the child is in an optimal program with family involvement, and her learning curve has leveled off in all functional areas for 2 to 3 years.

Severe Attentional and Learning Problems

There are two challenges in working with children with severe attentional and learning problems. The first challenge is working with them in relation to their underlying processing patterns rather than working only on their symptoms or behaviors. For example, a motor-planning and sequencing problem will make it difficult for a child to plan and organize actions, such as doing homework or lining up the numbers to do math problems. An auditory processing problem may make learning to read difficult because of poor sound discrimination (i.e., poor phonemic awareness). Underreactivity to sensations such as touch, pain, and sound may lead to sensory craving, increased activity, and poor attention.

The other challenge for clinicians is to look at all areas of functioning. There is a tendency to focus only on the circumscribed learning, attentional, or processing problems and ignore how, for example, they may influence areas of social and emotional functioning. For example, the same visual-spatial and motor-planning problems that may make planning and organizing school work and math difficult may also make it difficult for a child to interpret other people's facial expressions and body posture, which leads to social and emotional misperceptions. This type of emotional problem is not a reaction to frustration or feelings of failure but a direct consequence of the same processing problems that make school-

work difficult. Therefore, circumscribed attentional and learning problems, even if seemingly localized to school, require a comprehensive functional developmental evaluation.

A child's cognitive challenges and changing abilities should be continually assessed. Access to services should not be delayed pending a definitive diagnosis but provided to a child based on the individual profile of functional developmental impairments. If necessary for administrative purposes, a provisional diagnosis can be used.

A COMPREHENSIVE, DEVELOPMENTALLY BASED APPROACH TO INTERVENTION

A functional approach to assessment leads to a comprehensive approach to intervention that deals with all the relevant functional areas in an integrated manner. An essential part of intervention is a review of the child's functional developmental profile based on assessments of the child's functional developmental level and capacities, individual processing differences, and the different interaction patterns available at home and school, with peers, and in other settings. The functional assessment is updated in an ongoing manner with continuing clinical observations as part of the intervention. These ongoing observations are the basis for revising the child's intervention program.

A comprehensive intervention program involves working with the emotional interactions between the child and family to support each of the child's critical developmental capacities and related underlying processing differences. This Developmental, Individual Differences, Relationship-based (DIR) approach can be conceptualized as a pyramid. Each of the components of the pyramid build on each other and are described briefly in the following sections and by Figure 1.

Protective, Stable, Secure Relationships

At the foundation of the intervention pyramid are the protective, stable, developmentally supportive relationships and family patterns that all children require, especially those with developmental challenges. This foundation includes physical protection and safety and an ongoing sense of security. Some families require a great deal of support, therapy, or both in order to stabilize and organize these basic family functions. For example, some families may be dealing with extreme poverty and chronic states of fearfulness, abuse, and neglect. Some families require counseling to explore family patterns and relationships, particularly in connection to the challenges of coping with a child with special needs and the effects on relationships between spouses and siblings.

Intervention programs require staff trained to assess family needs, develop alliances, problem solve, and advocate, including advocating for social and economic support. They also need to provide family counseling and family or personal therapy where indicated (Barber, Turnbull, Behr, & Kerns, 1988; Bronfenbrenner, 1986; Dunst & Trivette, 1988; Powell, Hecimovic, & Christensen, 1992; Robbins, Dunlop, & Plienis, 1991; Turnbull et al., 1986; and Shanok, Chapter 14, this volume).

Ongoing, Nurturing, Trusting Relationships

At the second level of the pyramid are the ongoing and consistent relationships that every child requires. Typically developing children require nurturing relationships to help them achieve emotional and cognitive competency. Children with special needs, who often already have compromises in their

capacities to relate, are in even greater need of warm, consistent caregiving. Their caregivers, however, often face challenges in sustaining intimate relationships because it is so easy to misperceive their children's intentions. Understanding their children's behavior as attempts to cope with their difficulties or as being overwhelmed by their difficulties can often help caregivers recognize these misperceptions and develop more creative and empathetic ways of relating to their children. For example, children who are hypersensitive to touch may not be rejecting their parents' comfort and care. For such a child, parents may have to avoid light touch and use deep pressure to help the child feel more comfortable. Or, parents may need to understand that the child who jumps on a toddler who is crying may not be primarily aggressive but is so sensitive to the sounds of the cry that he panics and wants the noise stopped. Similarly, the child who has difficulty comprehending words may become confused and avoid communication. He may benefit from pictures or gestural signs to understand his environment and predict what will happen next in his interactions with caregivers. The child who is generally avoidant or self-absorbed may be underreactive to sensations, have low muscle tone, and need greater "wooing" to get beyond his self-absorption.

The importance of interactive relationships cannot be underestimated. Almost all learning occurs in relationships, whether in the classroom, with the family, or in therapeutic sessions. No one would deny that the ability to enjoy and participate in relationships is pivotal for learning to relate to others, experience intimacy and positive self-esteem, and develop healthy coping strategies. In addition, most cognitive or intellectual capacities learned in the first 4 or 5 years of life are also based on emotions and relationships (Greenspan, 1997a). For example, infants

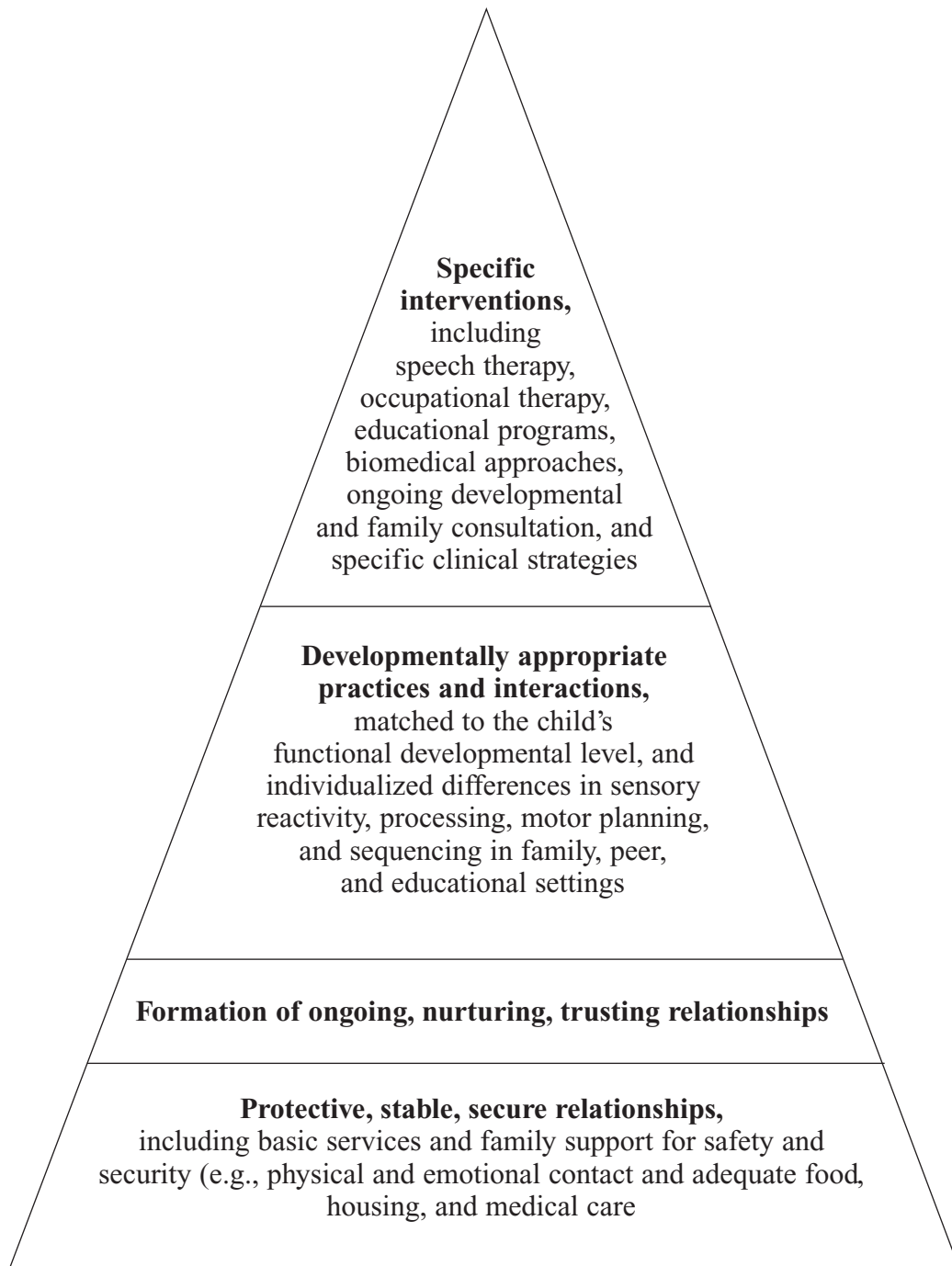


Figure 1. The Intervention Pyramid for Children with Special Needs

first learn initial concepts of causality in early relationships, as a smile lead to a smile back, crying leads to comfort, or reaching out leads to being picked up, rather than in activities such as banging objects on the floor, which leads to learning that this action makes a sound. Similarly, the meaning of words and gestures, the sense of time, and concepts of quantity are also learned as part of interactive, affective relationships early in life (Greenspan, 1997a). For example, for a toddler, “a lot” is more than she expects; “a little” is less than she wants. Words are connected to the emotional experiences that define them, and gestures become organized into patterns associated with emotions and expectation. For example, Dad’s smile leads to a hug and tickle.

Relationships serve a number of functions for young children. Most important, they must foster warmth, intimacy, and pleasure. In addition, relationships provide the context in which children experience security, physical safety, protection from illness and injury, and fulfillment of their basic needs. The regulatory aspects of relationships (for example, protection of the child from over- or understimulation) help the child maintain pleasure in intimacy and a secure, alert, attentive state that permits new learning and development to occur.

Relationships provide the basis for communication. Initially, the infant’s communication system is nonverbal. It involves affect cueing (smiles, assertive glances, frowns), contingent behavioral interactions (pointing, taking and giving back, negotiating), and the like. From the earliest reciprocal smiles to a child taking her mother’s hand, walking to the refrigerator, and pointing to a favorite food, there emerges a complex system of affective, gestural, and behavioral interactions that continues throughout the life of the individual. Even though this nonverbal system eventually works in conjunction with symbolic-verbal

modes of communication, it remains more fundamental: for example, adults tend to trust a person’s nonverbal nod or look of approval more than words of praise. The system of reciprocal affective gesturing enables the child to negotiate with his caregivers (environment) in small, graduated increments. Therefore, self-regulation improves and becomes context-dependent, and learning can become subtle and highly differentiated.

Relationships are, therefore, the context for learning which behaviors are appropriate and which are inappropriate (Greenspan, 1974, 1975). As children’s behavioral repertoires become more complex in the second year of life, discriminative and reinforcing properties of relationships define which behaviors increase and which behaviors decrease. Repertoires are built up through the give-and-take between children and caregivers (i.e., discriminative learning). In addition to behaviors, relationships help organize a child’s wishes, emerging self-perceptions, and a sense of self. The emotional tone and subtle affective interactions of relationships are, therefore, just as important as more easily observable behaviors.

Relationships enable a child to learn to symbolize experience. The first objects with which the child has a highly emotional experience are not playthings, but rather the human “objects” with which he interacts. In his interactions, the child goes from “acting out” his desires or wishes to picturing them in his mind and labeling them with a word. He goes from desiring Mom and grabbing her to saying “Mom” and looking at her lovingly. This transformation heralds symbolic awareness.

The ability to picture an object when it is displaced in both time and space is a much-used marker for the child’s achievement of *object permanence* and the emergence of symbolic capacities. Pretend or imaginative

play involving emotional human dramas (e.g., the dolls are hugging or fighting) helps the child learn the types of affective-based symbolization that will enable her to connect an image to a wish or intent and then use this image to think, “If I’m nice to Mom, she will let me stay up late.” Figuring out the motives of a character in a story as well as the difference between ten cookies and three cookies will depend on the child’s capacity for affective symbolization (Greenspan, 1997a).

The child’s ability to create mental pictures of relationship and, later, other objects, forms the basis for more advanced symbolic thinking (Greenspan, 1997a & b). For example, a key element essential for future learning and coping is the child’s ability for self-observation, problem solving, and creative thought. The ability to self-observe is essential for self-monitoring of activities as simple as coloring inside or outside the lines, or matching pictures with words or numbers. Self-observation also helps a child label rather than act out feelings. It helps her to empathize with others and match behavior to the expectations of the environment.

Self-observation is essential for advanced learning and social negotiation. The ability for self-observation emerges from the ability to observe oneself and another in a relationship and is a product of the same emotional interactive relationships as earlier abilities. Similarly, advanced cognitive skills involving numbers, reading, and analytic thinking build on fundamental, relationship-based capacities. As relationships embrace symbolic capacities, language grows from words to sentences and concepts derived from daily affective experiences. Similarly, cognitive capacities involving time and space emerge out of the day-to-day negotiation of waiting or not waiting, or of having a little more or less of this or that. Even reading comprehension abilities blossom from the natural give-and-take of

dialogue with parents. The child can only understand the meaning of the words or pictures in a book in the context of her daily emotional experiences with others. Without emotional experience to abstract from, there would be no symbolic meaning.

The starting point for mobilizing growth involves meeting a child at his current functional developmental level and forming a relationship and engaging in emotional interactions at that level. Children will vary; some are unrelated and unpurposeful and require work on engaging and intentional communication whereas others are purposeful but require extra help in using symbols. Still others use symbols or ideas in a fragmented way and need to learn how to be logical and more abstract. For each developmental level, special types of interactions can enable a child to master that level and its related capacities.

To support the child’s ability to relate requires a significant amount of time, consistency, and understanding. Family difficulties or frequent turnovers among childcare staff or teachers may compromise the requirement for consistency in a child who is beginning to learn how to relate to others.

Developmentally Appropriate Practices and Interactions

At the third level of the pyramid lie consistent relationships and interactions that have been adapted to the individual differences and functional developmental needs of each child, which can be thought of as *developmentally appropriate practices and interactions* for the child with special needs.

Developmentally appropriate practices must characterize family and all other interactions, including home and educational programs. They should also be integrated into the different therapies. Developmentally appropriate interactions and practices, how-

ever, are not always easy for caregivers, educators, and therapists to implement. The child's tendency for self-absorption, perseveration, self-stimulation, impulsive actions, or avoidance often elicits counterreactions that attempt to alter the child's immediate behavior rather than to build interactions that will both promote growth and alter the immediate behavior.

Children who do not have special needs often involve themselves in what the National Association for the Education of Young Children (NAEYC) has described as developmentally appropriate practices: that is, they play on their own (part of the time) or with peers, siblings, or parents interactively and using developmentally appropriate toys, games, and puzzles in a constructive, growth-facilitating manner. For children with special needs who, because of their processing difficulties, may find it very hard to interact with people or toys in a way that facilitates their development, the challenge is to help them become involved in their own special types of developmentally appropriate practices and interactions. Doing this involves using the profile of the child's functional developmental level, individual differences in sensory processing, sensory modulation, motor planning and sequencing, and caregiver and family interaction patterns to construct interactions that will be pleasurable as well as developmentally meaningful and facilitating. For example, a 4-year-old may only have the intermittent functional capacities of a 2-year-old, understand visual-spatial experiences better than auditory ones, and be oversensitive to sensations. The focus, therefore, should involve working on engaging, gesturing, and beginning to elaborate symbols by using a lot of visual support and pretend play in a very soothing and regulating context. (See Greenspan & Wieder, Chapter 12, this volume.)

Home-Based Component

Children spend many hours at home. When a child has severe processing difficulties, his choice of activities may *not* be developmentally appropriate or facilitating, such as hours of television-watching, perseverative behavior, or repetitive computer games. Children generally are happier, more productive, less stressed, and make more progress when involved in *developmentally appropriate interactions and practices*. In fact, these types of interactions in the home can become the most important factor for aiding a child's growth.

Developmentally appropriate practices often require one-on-one work with the child. Parents must decide how much they can do on their own and how much help to elicit from volunteers, hired students, or home visitors from community, state, or county-supported intervention programs (e.g., wrap-around services in the state of Pennsylvania provide a very useful model in which bachelor's and master's level professionals often spend more than 20 hours a week supporting the program at home).

The home-based component of developmentally appropriate interactions and practices can be divided into two parts. One involves developmentally appropriate interactions based on following the child's natural interests and emotional inclinations. The other focuses on semistructured problem-solving interactions that also harness the child's "affect" but involve semistructured created situations to facilitate mastery of specific processing capacities, and emotional, cognitive, language, and motor skills. These two components of the home-based program are described in the following sections.

Following The Child's Lead

The caregiver should follow the child's emotional interests to engage him at his functional developmental level and challenge him

to move to the next level, thereby gradually moving the child toward negotiating the six levels outlined in Chart 1. These spontaneous interactions in which the caregiver follows the child's lead will often take on two qualities. First, the caregiver helps the child move in the direction that interests him by, for example, putting the ball the child is interested in on her head. The child may then take the ball off the caregiver's head, thus being drawn into focusing on the caregiver and engaging in pleasurable relating and purposeful, two-way communication. Second, the caregiver can become playfully obstructive. For example, if the child perseveratively opens and closes doors, the caregiver could get "stuck" behind the door. This action leads the child to focus on the caregiver as he tries to push her away from the door, giggling as he succeeds—only to have the caregiver run back to the door again to resume the game. In this way, the caregiver facilitates focus and engagement. As the child purposefully tries to engineer moving the caregiver away from the door, intentional, two-way communication is facilitated. Eventually, complex problem-solving behaviors and even the use of words, such as "go" or "away" can be elaborated off of the child's spontaneous, emotional interest in the door. (Strategies for the spontaneous use of developmentally appropriate interactions to help the child master each of the six core functional emotional capacities are described in detail in Greenspan & Wieder, Chapter 12, "Developmentally Appropriate Practices and Interactions.")

Semistructured, Problem-Solving Interactions

The caregiver should create learning challenges for the child to master. These may involve social, motor, sensory, spatial reasoning, language, and other cognitive skills. For example, if the goal is to help a child learn a

new word, such as "open," the caregiver might put the child's favorite toy outside the door so that she would want to open it. The caregiver may then help the child imitate the word "open." The child, in this way, is practicing gesturing and using words together. Imitating the sounds "ope" for "open" while opening the door also provides the child with immediate meaning. Tying the word to affect or intent (and meaning) facilitates generalization. This approach is in contrast, for example, to the child saying the word "open" in response to a picture card and only later trying to use the word in real life to solve a problem.

In addition to working on language and cognitive and social capacities, semistructured problem-solving interactions should focus on activities that enable the child to engage in (1) sensory modulation and motor-planning exercises, such as jumping on a trampoline or mattress, running, spinning, appropriate roughhousing with deep tactile pressure, and obstacle courses; (2) perceptual-motor exercises and looking and doing games, such as throwing and catching a big Nerf ball, kicking, and reaching for moving objects; and (3) visual-spatial exercises, such as treasure hunt games, hide-and-seek, and building complex structures from visual cues.

In general, it is most effective for the child's therapeutic team, including parents, educators, speech pathologists, and occupational therapists to meet weekly to design the functional goals for the semistructured aspect of the home-based intervention. At least one-third to one-half of the child's available time at home should be spent on spontaneous interactions (following the child's lead and working off of natural affect and inclination to foster the six functional levels described earlier) and the remaining two-thirds to one-half on developmentally appropriate, semistructured problem-solving activities.

Semistructured, problem-solving activities also need to be geared to each child's unique profile. When put into a problem-solving context with emotional intent, the following types of activities may also be included:

- *Imitating new words and using concepts* that help the child solve a problem he wants to solve, for example, “open,” “up there,” or “go.”
- *Motor-based challenges*, such as gross-motor movement, balance, movement in space, running, jumping, spinning, perceptual-motor activities (involving looking and doing and crossing the midline).
- *Spatial problem solving*, such as treasure hunt games in which the child is given clues about how to find her favorite toy, first in the box in front of her and, eventually, in the box upstairs near another box behind the blue chair.
- *Motor-imitation exercises*, such as copying the caregiver by touching eyes, ears, nose and, eventually, vocal (sound) imitations leading to word development.
- *Spatial and quantity concepts*, such as “here,” “there,” “big,” “little,” and, eventually, including “more” or “less,” and association of numbers, time, or distance (e.g., finding Mommy in different parts of the house, negotiating one versus three cookies, or showing with hands the difference between a little and a lot).
- *Facilitation of conceptual understanding* by using cards where the word is under the picture and is used to help the child get the juice or a favorite toy, or as a cue for pretending what the word or sentence conveys.
- *Visualization exercises*, as the child becomes older, to help the child picture words, sentences, or quantities ($2 + 2 = 4$) to facilitate a deeper understanding of concepts. These concepts may also be acted out.

Specific therapies often work in a semi-structured manner on these types of important capacities. (See the Table of Contents for related chapters.) Team meetings should suggest the goals of this part of the home program.

Peer Interaction

Peer play is especially important once the child has mastered preverbal problem-solving skills and is moving into the early stages of using ideas in a functional and spontaneous manner. The now-engaged, intentional, partially verbal, and imaginative child needs to practice his emerging skills not only with adults but also with other children who are at a similar or higher developmental age (i.e., the other children need to be interactive, somewhat verbal, and imaginative). However, the playmates need not be the same age as the child. For example, if the child is 4½ years old, but has a functional, emotional developmental capacity of 3 years, he might prefer the company (and vice versa) of 3-year-old playmates.

At this point, individual, one-on-one play dates should occur four or more times per week for one hour or more. Initially, an adult may have to facilitate the interactions to help deter the children from drifting into parallel play. The adult may create a game to help the children work jointly, such as having both children hide together while the adult tries to find them. While following the children's lead, the caregiver is also free to create games that facilitate interactions among the children. The goal is to help the children “rub shoulders” with each other and to communicate with gestures and words.

The need for peer play occurs at about the same time that a child needs to be integrated, often with an aide, into a regular preschool program or into an ongoing inclusion or integrated program.

Setting Limits, Facilitating “Compliance”

Developmentally appropriate practices used to foster new functional capacities can help parents, clinicians, and educators with one of their most difficult challenges—how to integrate the process of setting limits and compliance with other clinical and educational goals. Following rules and maintaining safety are understandable goals. Not infrequently, however, the need for compliance and control takes the form of strapping a child into a chair, physically forcing him to walk to the bathroom, or using other types of restraint.

The key to teaching a child to follow rules is to provide developmentally appropriate practices and interactions that meet the child at his functional developmental level in the context of his individual differences. For example, for a child who is impulsive and is not yet capable of logical, verbal thinking and conversation, developmentally appropriate interactions mean a one-on-one aide working with the child on the basics of relating and purposeful interaction. The back-and-forth signaling, which will include limits, however, will be of the type one would implement with a 1- to 2-year-old child. Through this type of one-on-one interaction, the child gradually learns how to be a purposeful, preverbal communicator. Gradually, responding to limits becomes a part of this purposeful communication. Expecting a child who can not yet negotiate basic needs with a series of back-and-forth signals to follow group-oriented rules will often result in frustration, anger, impulsive behavior, and, more importantly, slower progress. Developmentally appropriate practices are more likely to tap into potential plasticity from within the individual child’s own brain than will externally-imposed structured techniques (i.e., too complex or restrictive) that bypass neural networks already in place.

As a child makes progress and is purposefully interactive, both encouragement and sensitive limits can help him work with groups of children and follow expectations. Dangerous, as opposed to noncompliant, behavior needs to be dealt with immediately with firm but gentle limits. These limits should be based on the child’s functional developmental capacities, not on actual age or expectations for the other children in a group. Just as Congress has appropriately mandated that a child be educated in the least restrictive environment, therapists should teach the child the *least restrictive, developmentally appropriate* tactics to control his behavior and be sensitive to the needs of others.

Specific Therapies and Educational Strategies

At the apex of the pyramid are the specific therapeutic and educational techniques that build on and also facilitate the child’s basic capacities for attention, engagement, intentional two-way communication, and the creative use of symbols. In this way, new capacities are tied to the child’s sense of purpose and self (i.e., his affects). Integrating therapeutic strategies into the child’s naturally occurring interests and activities can be very helpful in simultaneously fostering her capacities to initiate, engage, communicate, problem solve, and think, as well as learn new functional skills. While new skills are on the ascendancy, perhaps in relation to maturational shifts, is an optimal time to intensify a particular therapy that supports that skill, such as physical therapy to facilitate walking.

A variety of strategies have been advocated. Some attempt to offer a comprehensive approach whereas others focus on specific issues. However, an approach cannot be truly comprehensive unless it works with all the levels of the pyramid. Both focused and partially

comprehensive approaches must build on the foundation previously described. These include educational approaches (e.g., Bailey & Wolery, 1992), cognitive, language, sensory, and motor processing approaches (e.g., Prizant & Wetherby, 1988; Bricker, 1993), peer models (Odom & Strain, 1986; Strain, Shores, & Timm, 1977), behavioral approaches (Lovaas, 1980, 1987; Durand, Berotti, & Wiener, 1993; Haring & Lovinger, 1989; Odom & Haring, 1993), work with family patterns (e.g., Barber et al., 1988; Bronfenbrenner, 1986; Dunst & Trivette, 1988; Powell et al., 1992; Robbins et al., 1991; Turnbull et al., 1986), interactive “floor time” approaches (Greenspan, 1992; Greenspan & Wieder, 1998), and work with the social milieu (e.g., Ostrosky, Kaiser, & Odom, 1993; Wolfberg & Schuler, 1993).

Speech and Language Therapy

Speech-and-language therapy is especially helpful for preverbal, as well as other types of symbolic communication (e.g., verbal, pictures, signs). It can also be especially valuable for oral-motor work and related expressive language challenges. Three or more individual sessions per week of 30 to 60 minutes each is often required, in addition to consultation to and integration with the home and educational program. (See Gerber & Prizant, Chapter 5, and Madell, Chapter 6, this volume, for further discussion.)

Occupational and Physical Therapy

Occupational and physical therapy are especially helpful for motor problems, motor-planning and sequencing difficulties, and sensory modulation and processing challenges. Two to three individual sessions per week of 30 to 60 minutes each is often required, in addition to consultation to and integration with the home and school programs.

There is often confusion between very helpful clinical strategies that foster sensory modulation, muscle tone, and motor planning and debates about the explanatory value of sensory integration theory. Like all broad theories, time and continuing research will be needed for further refinement of sensory integration theory. In the meantime, clinical techniques that enable children to master functional developmental capacities should be employed based on their clinical usefulness. (For further discussion, see Williamson, Anzalone, & Hanft, Chapter 8; Long & Sippel, Chapter 9; Koller, Chapter 11; Wachs, Chapter 20; Youssefi & Youssefi, Chapter 21; Feuerstein, Chapter 22, this volume.)

Educational Program

An educational program should be geared to a child’s functional developmental capacities and processing profile and must involve developmentally appropriate practices for children with special needs. For example, some programs attempt to have a child learn in a group even though the child requires a highly individualized approach. Often, children are able to learn in groups only after they have advanced to the point of mastering individual relationships and preverbal problem-solving interactions and are already beginning to use words. Nonetheless, school settings with other children can be very enriching, even if initially most of the work is conducted on an individual basis. Gradually, learning can move more toward group interactions.

A child who is not yet engaged or purposeful needs to be involved in one-on-one interactions with a teacher, aide, or volunteer throughout most of the school day. The aide’s role is not to sit behind the child or help the child conform to noninteractive routines, but rather to “woo” the child into learning interactions (i.e., two-way purposeful interactions

and a constant flow of back-and-forth communication). Once a child progresses to purposeful gestural communication, complex imitation and, over time, to using symbols (e.g., words, pictures, and signs) and is able to relate to and communicate logically with peers, two-way symbolic interactions need to be facilitated to promote logical thinking. As a child becomes more logical and abstract, group learning and routine academic activities can provide constructive learning opportunities. This stage, however, is the culmination of a long learning process.

Many programs are not equipped to provide the needed one-on-one interaction for most of the school day, which is required by the child who has not yet fully learned to engage with peers and adults or communicate and problem solve with gestures. In addition, education for children with special needs may take many forms. Often, goals are derived from the academic objectives for older children. When this occurs, there is often little attention given to the sequence by which young children acquire the core functional abilities that will enable them to relate, communicate, think, and learn, including mastering traditional academic tasks. Typically, there is an overemphasis on compliance in a group situation before a child has learned to negotiate one-on-one relationships or even understand simple expectations. For example, a child may be taught in a rote manner to match shapes before she can engage in basic multistep, preverbal, problem-solving interaction sequences, such as getting a toy out of a box, bringing it over, and motioning for an adult to play.

The child who is already attentive, engaged, purposefully interactive, involved in complex, ongoing preverbal problem-solving communication (i.e., gesturing), and is beginning to use words presents special opportunities. She needs to learn to elaborate and build bridges between

ideas in a variety of contexts. To meet this goal, the child requires opportunities to interact with peers (one-on-one and in small groups) who are related, interactive, and verbal (often with an adult mediating). She requires an integrated setting or an aide in a mainstream setting.

It is important to emphasize that educational programs for a child with special needs should not comprise a series of disconnected cognitive learning opportunities. The important academic goals just stated do not emerge as isolated cognitive skills by simply practicing them. Having a child sit and look does not mean he understands or that he can learn from listening. Nor does having a child memorize a passage mean he understands it. These skills are part of a progression where each step builds on another. Comprehension, relating, communicating, reading, math, writing, and engaging in higher-level problem solving must build on the six functional capacities described earlier. Education programs should identify where each child is in his unique progression, meet the child at his level, and work on the next steps. *Only this type of logical progression constitutes developmentally appropriate practices for a child in school.*

For example, to read with meaning or to understand math, a child must learn how to:

- “*Want*” to attend and engage with others (first with one person at a time and then a few) in order to be part of experiences that will enable him to discriminate sounds and sights necessary for reading and math, and to eventually give words and quantity concepts meaning.
- *Communicate logically with simple gestures and affect cues*, and then with complex problem-solving behaviors in order to understand patterns of cause-and-effect relationships and different levels of logic. These capacities are essential for any type of academic work.

- *Represent or symbolize emotional experiences and build logical bridges between them.* What a child knows from preverbal experience as well as new verbal experience must be understood, communicated, and thought about logically with words, pictures, or other symbols. This is necessary for creative and logical thought, abstract thinking, and all academic tasks requiring the comprehension of words or the ability to reason with symbols.

In addition to the difficulties in providing one-on-one interaction, most educational programs, due to administrative policies, change intervention teams for a child and family when the child is 3 years old. For a child with autistic patterns who is learning to relate to and trust others, this change can undermine educational progress. Therefore, continuity of staff and program is critical during the infancy and preschool years.

Developing the most appropriate educational program for children with special needs is extremely challenging and often requires one-on-one or very small group learning. To increase one-on-one learning opportunities that enable children to climb the developmental ladder and eventually learn and communicate in groups, school programs should provide more aides and allow parents to volunteer, as they do in cooperative preschools. (See Wieder and Kalmanson, Chapter 13, this volume, for further discussion.)

Children with learning and attention problems who have progressed and mastered their basic challenges in relating and communication, as well as children who have already mastered these skills but have problems with attention, learning, or both, require an educational program that provides opportunities to resolve specific processing challenges and progress to high levels of abstract thinking and academic proficiency. Promising techniques

to strengthen processing capacities such as visual-spatial, auditory, and motor planning are being developed and are available in innovative schools and programs but are not yet sufficiently available in all education and special education programs. (See Miller and Eller-Miller, Chapter 19; Wachs, Chapter 20; Youssefi & Youssefi, Chapter 21; Feuerstein, Chapter 22; and Bell, Chapter 25, this volume.)

In addition, many intelligent children with moderate to severe circumscribed learning and/or attention problems who are fully capable of being mainstreamed often require both participation in regular classes and one-on-one and very small-group (two to four children) learning opportunities to master specific processing challenges. Many require special learning opportunities for as much as half of the day, during which they can work on their processing challenges with the most up-to-date techniques. At present, unfortunately, many children with learning and attention problems do not get the adequate time or techniques they require.

Exploration of Biomedical Interventions

Certain children with special needs will benefit from biomedical assessments and considerations of interventions, including medications. For example, medications in the selective serotonin reuptake inhibitor group may facilitate motor planning, sequencing, and attention and reduce perseverative or repetitive behavior. To determine if a biomedical intervention should be a part of the therapeutic regimen, a basic biomedical assessment needs to be implemented, as described by Robinson, Chapter 17, on biomedical approaches.

In exploring a trial of medication, it is essential to look carefully at the side effects and weigh the benefits and risks. Medications

are not designed as precisely as would be optimal and will often affect nontargeted areas. In addition, exceptional caution and close monitoring are required if more than one medication at a time is being considered.

Ongoing Developmental and Family Consultation

In addition to conducting the initial diagnostic evaluation and monitoring progress, developmental specialists (e.g., a psychologist, behavioral or developmental pediatrician, or child psychiatrist) may be helpful in facilitating or coaching the family in constructing developmentally appropriate interactions at home and at school. For some families, this consultation may take the form of regular meetings one or more times per week, during which the therapist works with the parents and other caregivers on their interactions with the child and, if needed, works directly with the child. Consultations may also involve periodic home visits. In addition, intensive family work with supports and coordination from community agencies will be necessary for some families. The form the consultation takes will vary depending on the needs of the child and the family. (For a more detailed discussion, see Greenspan, 1992; Shanok, Chapter 14, this volume)

Family Support and Dynamic Family Processes

Special clinical techniques are often needed to support families. Although there is a long tradition of family-based programs for children with special needs, many of these programs offer only minimal help to the whole family, including siblings. Marital conflicts, misperceptions of the special-needs child or her siblings, and higher levels of stress may characterize the family functioning. It is also difficult for a family to orchestrate an entire

intervention program. Often, various levels of support are needed.

SPECIFIC CLINICAL TECHNIQUES

Specific clinical techniques to deal with difficult symptoms or behaviors are often needed as part of an overall program. There are two primary philosophies that tend to guide parents, educators, and clinicians. The behavioral approach attempts to decrease the target behavior directly by ignoring it, using negative consequences, or both, and attempting to replace it with another behavior supported by positive consequences (e.g., interrupting perseverative behavior and insisting on and reinforcing another activity). Intensive behavioral approaches are often suggested as an overall treatment method. Although they have a circumscribed role for selected children, they do not address many important functional capacities, including the capacity to relate with pleasure and warmth, to connect affect or intent to motor planning and emerging symbolic capacities (for creative and reflective thinking), and to process sensory information and plan actions.

Although behavioral approaches are widely used in most communities, as indicated in Chapter 3, children with typical patterns of autism who are in these programs generally do not make clinically meaningful progress. They are often unable to learn to live independently, work, and participate in a range of age-expected social relationships. (See, Chapter 3; and Tsakiris, Chapter 31, this volume, for a full discussion.) Nonetheless, specific behavioral exercises can be useful for a child who has severe motor-planning problems and, therefore, is having difficulty learning to imitate actions, sounds, and words. When the child can begin using imitative capacities at the moment he is trying to solve a problem, such as copying the act of opening

a door to get out, or saying “up” to get his toy from a high shelf, he can move into more dynamic, interactive learning approaches. Therefore, as one part of the semistructured component of a broad comprehensive program, some children may, for a period of time, require behavioral exercises in conjunction with dynamic, interactive work.

Intensive behavioral intervention techniques by themselves tend to be almost antithetical to harnessing the child’s natural affect and intent as a basis for internal control and initiation of behavior and language. They have as their strength the external control of behavior through external discriminative and reinforcing stimuli (prompts and reinforcers). External control can help get some behaviors started. While there has been the hope that internal prompts and reinforcers can take over as part of a generalization process, the child does far better if she can learn new behaviors and concepts under the influence of internal affect cues. These give her actions immediate meaning and direction.

Intensive behavioral intervention techniques can be compared to the strategy of a tennis coach using hand-over-hand learning. In this approach, the coach holds the racket with the student and drops the ball in front of the student *only* when teaching a difficult, new handgrip or stroke. Most of the learning occurs either through playing actual games or in dynamic drills where the student is learning to use his forehand or backhand while on the run. The behavioral strategy is similar to the hand-over-hand approach because a therapist uses it temporarily to shore up a skill such as imitative capacities. Once the child reaches a certain level, however, most of the learning needs to occur in the semistructured learning situations (such as the dynamic tennis drilling) and in the spontaneous learning interactions (such as playing games). The more structured approach would remain

available on an as-needed basis. In this way, behavioral strategies are part of the tactics that are available to the clinician.

Interestingly, developmentally appropriate practices can be conceptualized in behavioral terms. In this model, the focus is on developmental processes (i.e., classes of behavior), such as creative, ongoing reciprocal interaction (circles of communication) rather than on specific behaviors, such as “looking.” The processes selected for focus are from a hierarchy of developmental capacities that need to be mastered. The cues (discriminative stimuli) and reinforcers are based on internal affect states rather than on external events (i.e., natural social cues and reinforcers). Interactions are continuous rather than stop-start. Some intensive behavioral approaches are moving toward such a developmentally based model (e.g., Pivotal Response Training [(Schreibman, Stahmer, & Pierce, 1996)]).

The functional, developmental approach attempts to understand the broad category of functioning that the worrisome behavior is part of, and the broad functional categories that may be missing. In this context, functional means a broad developmental capacity essential for the child’s progress, such as purposeful gesturing or using ideas. It does not refer to a narrow functional behavior, such as dressing. Developmentally appropriate interactions and practices are used to help the child master new functional capacities. For example, repetitive opening and closing of a door is part of the larger category of repetitive and rigid ways of dealing with the world. The missing functional category is the developmentally more advanced capacity for flexible, creative interactions in the world. In this model, the worrisome, repetitive behavior serves as an opportunity for progressing to higher functional developmental levels of flexible, creative interactions. Therefore, as described earlier, a perseverative behavior,

such as opening and closing a door, is turned into a purposeful interaction. The functional developmental approach keeps the larger therapeutic goal of higher-level functional developmental capacities in the forefront.

Both philosophies can be used in an integrated manner. For example, a caregiver can interrupt a child's self-injurious behavior while simultaneously drawing him into interactions that serve a similar sensory need, such as deep tactile pressure coupled with warm engagement and two-way intentional communication.

SUMMARY

This chapter reviewed the general clinical principles that characterize a functional developmental approach to assessment and intervention. The chapters that follow review intervention research, examine the evaluation and intervention process for each functional area, and explore the evaluation and diagnostic process as well as the intervention process in more detail. Relevant neuroscience research also is considered. ■

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