

**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,

<b>Functional Developmental and Processing Capacity</b>	<b>Percent of Patients</b>	<b>Description of Functional Developmental and Processing Pattern</b>
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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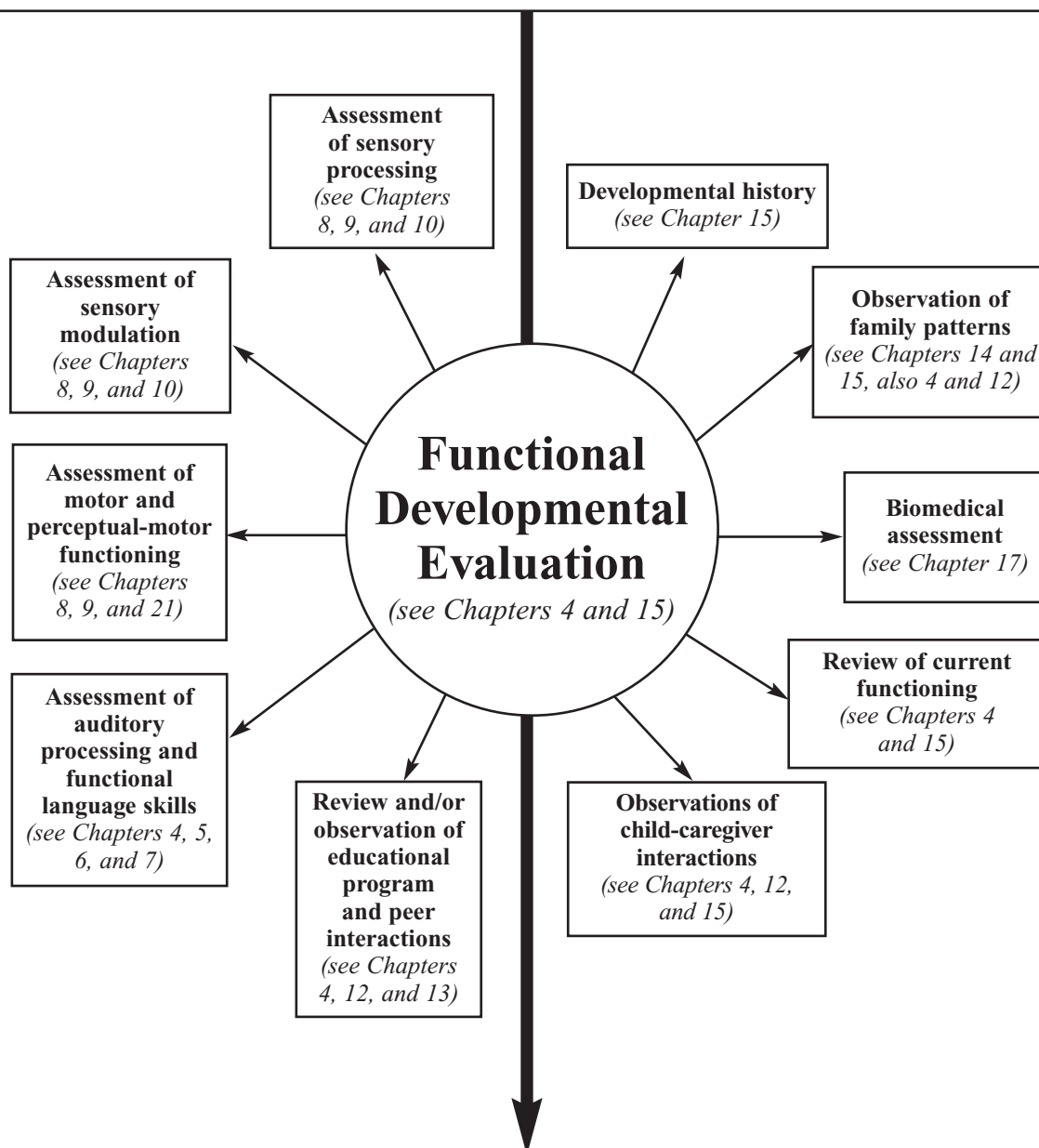
## Appendix A

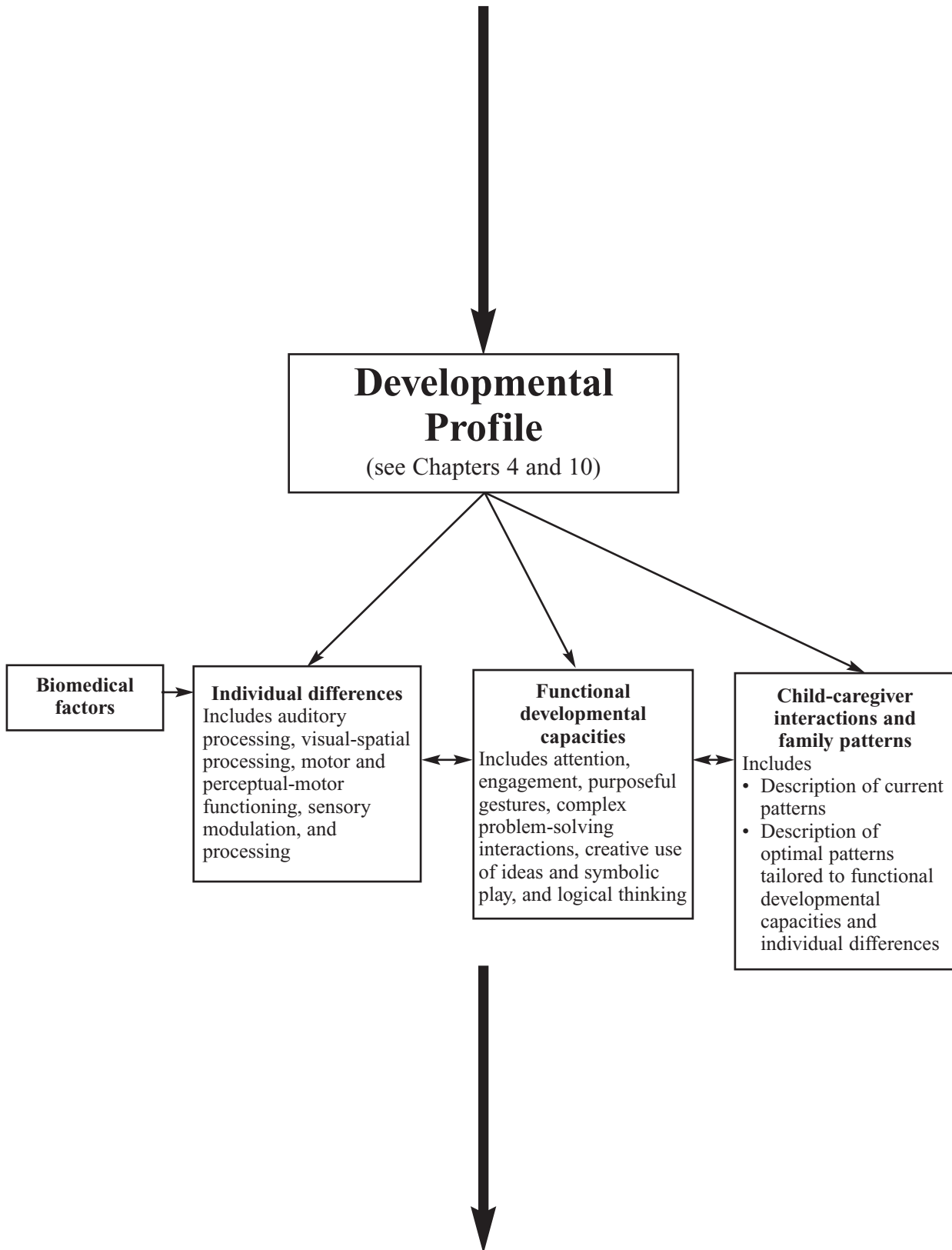
## OUTLINE OF THE DIR MODEL

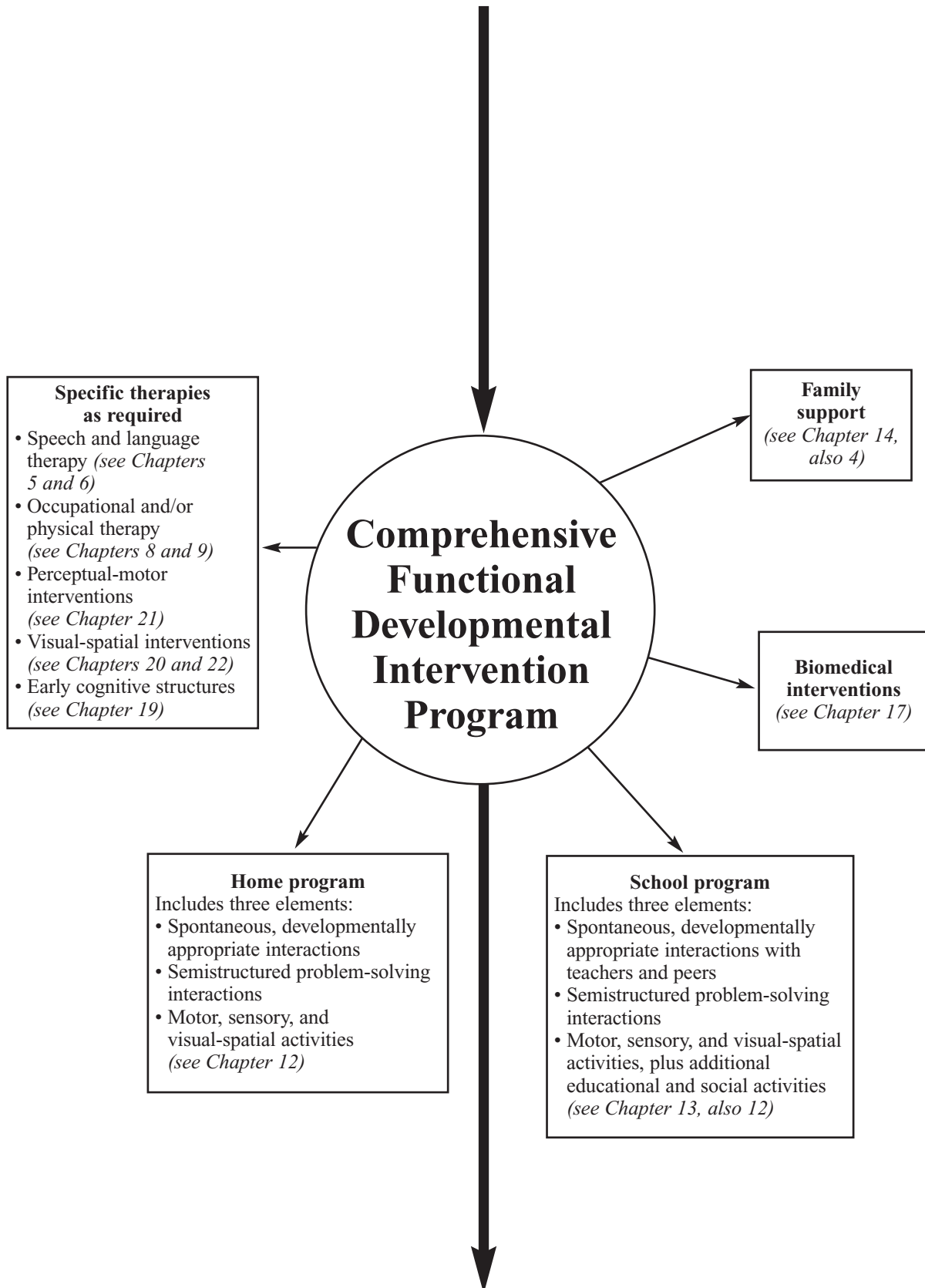
### How to Use *The ICDL Clinical Practice Guidelines*

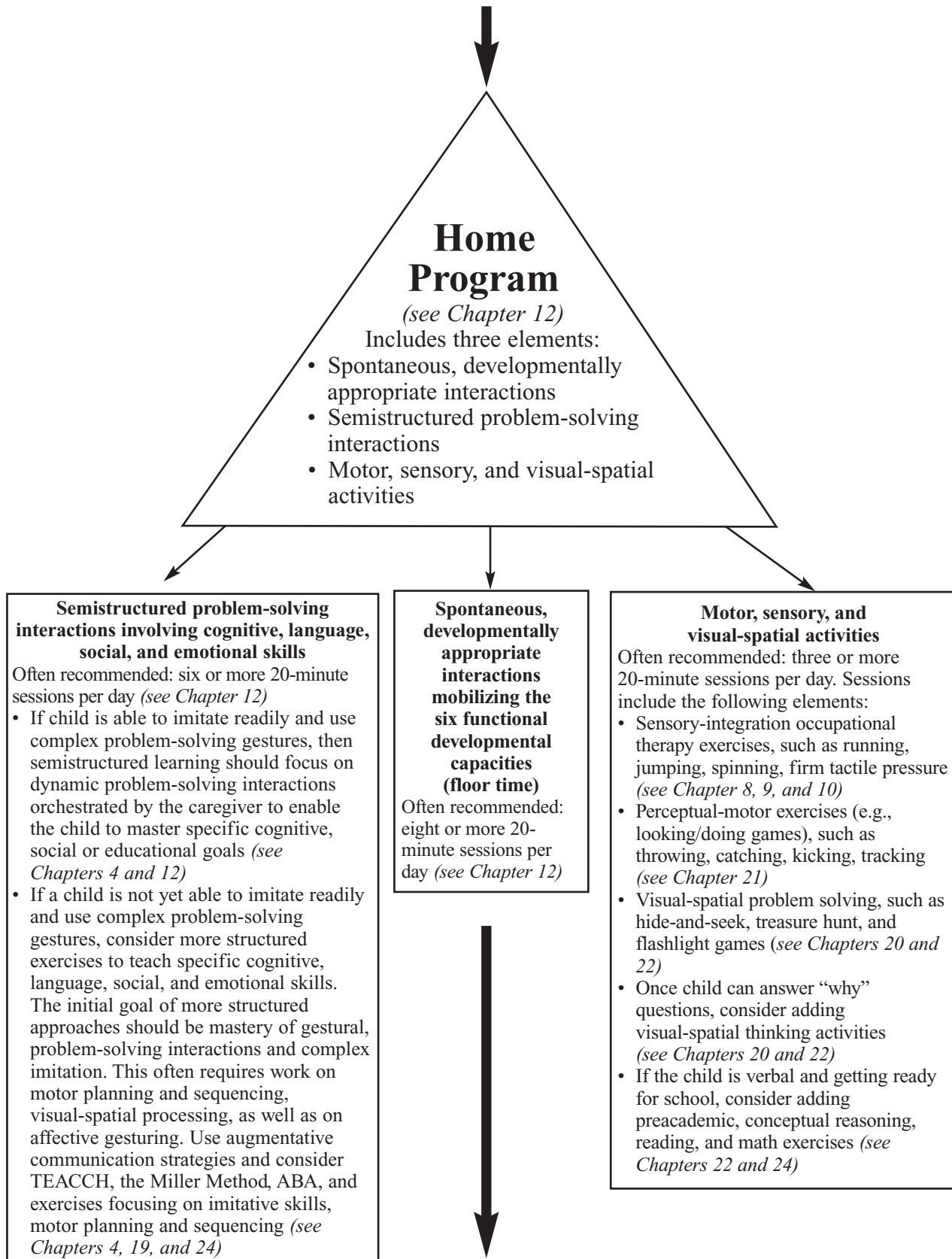
#### Screening (Functional Developmental Growth Chart)

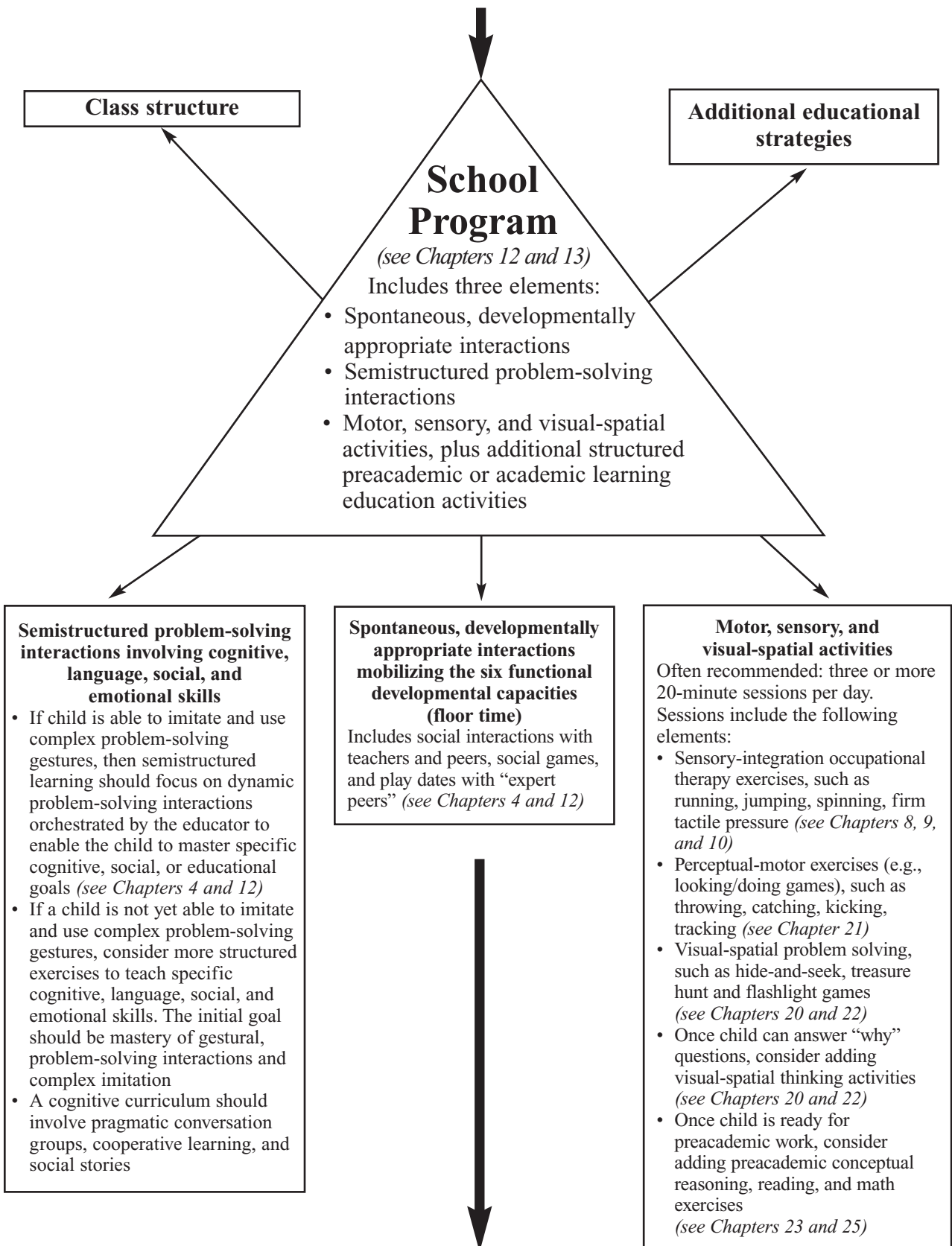
If at any time during the early years, a child experiences a loss or lack of progress in developing long chains of emotional cueing—regardless of other symptoms—proceed to a **full, functional developmental evaluation**. Most commonly, the loss or lack of progress in developing a continuous flow of reciprocal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

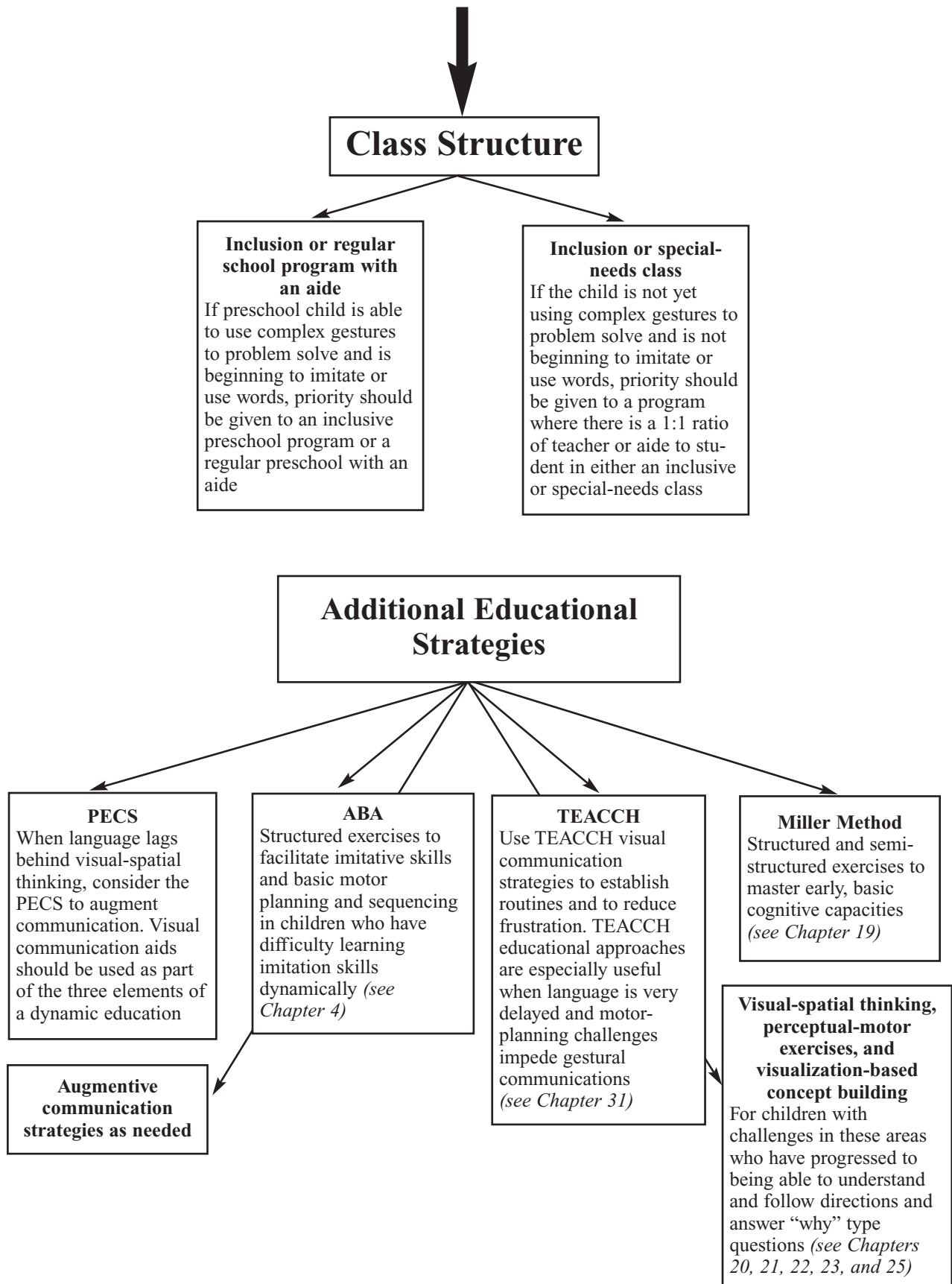












## Appendix B

### 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).

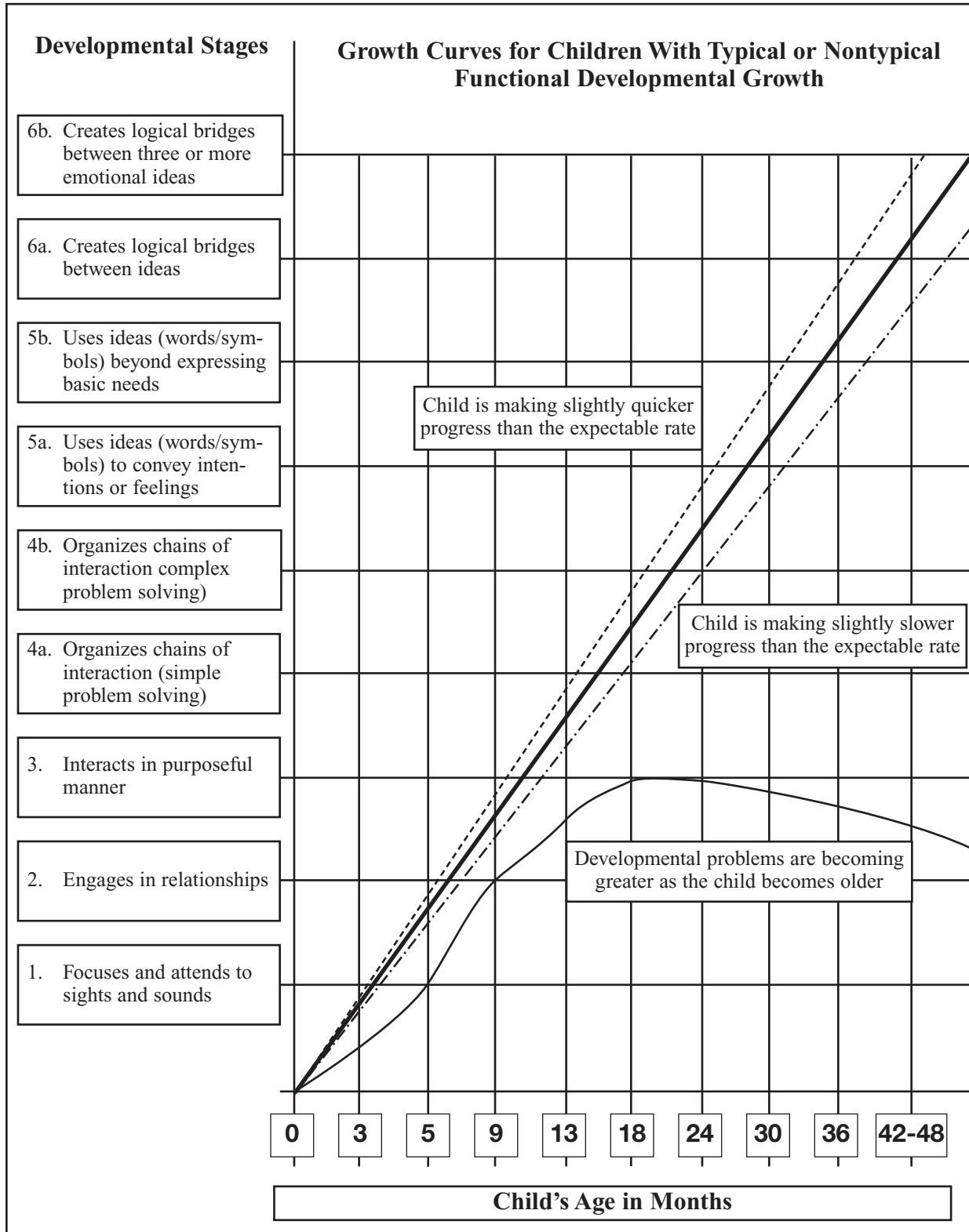
In order to broaden the frame of reference and implement the first level of monitoring an infant or child's progress, it may prove

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

**Figure B1. The Functional Developmental Growth Chart**



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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