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The Need for a Comprehensive Individualized Approach

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

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

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

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

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

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

Recent clinical observations and research suggest that there are three interrelated processes that are essential for mobilizing a child's development. The first process is working with each child's individually different underlying processing capacities, such as sensory modulation, auditory and visual-spatial processing, and motor planning. The second process is working with a child's most important functional developmental capacities (the building blocks of intelligence and emotional health), such as shared attention; relating with intimacy; engaging in gestural and affective reciprocal and social interactions; and using ideas meaningfully, creatively, and logically. The third process involves utilizing new insights into the role of relationships and emotional interactions in facilitating a child's intellectual and emotional growth. For example, the earliest cognitive structures and sense of causality do not, as Piaget believed, first arise from early sensorimotor (cognitive) explorations but from even earlier affective interactions between a baby and his or her caregiver (e.g., a smile begetting a smile). At each stage of early cognitive development, emotional interactions lead the way. The meaning of words, early quantity concepts ("a lot" to a $2^1/_2$-year-old is more than he expects; "a little" is less than he wants), logical and abstract thinking, and even important components of grammar depend on specific types of emotional interactions (Greenspan, 1997; Greenspan & Wieder, 1999). These new observations make it possible to construct individualized, affectively based, learning interactions and relationships to promote intellectual and emotional growth. These individualized interventions are based on each child's unique profile of processing differences and functional developmental capacities.

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

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

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

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

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

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

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

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

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

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

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

1. Determine the specific clinical principles and ingredients that should guide interventions for complex developmental disorders.
2. Develop methods to determine how to construct an individualized, comprehensive intervention program for a unique child (such as Robert) with his own profile of functional capacities and processing differences.

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

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

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

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