

CONTENTS

|   |     |
|---|-----|
| Editorial: A Developmental Model for Research on Interventions for Autistic Spectrum Disorders—Stanley I. Greenspan, M.D. & Serena Wieder, Ph.D.  | 1   |
| Special Commentary: Early Factors in Development and the Identification of At Risk Patterns—T. Berry Brazelton, M.D.  | 7   |
| Reflexes Gone Astray in Autism in Infancy—Philip Teitelbaum, Ph.D.,<br>Osnat B. Teitelbaum, Joshua Fryman, and Ralph Maurer   | 15  |
| Differences in Affect Cuing: A window for the identification of risk patterns for autism spectrum disorders in the first year of life—Stanley I. Greenspan, M.D. and Stuart G. Shanker, D.Phil. | 23  |
| Touchpoints and DIR: Common Ground—Joshua Sparrow, M.D.   | 31  |
| Chronic Pain and Pervasive Developmental Disorders—Brenda Bursch, Ph.D. and Lonnie Zeltzer, M.D.  | 41  |
| Case Studies of Graduate Students Implementing DIR Programs—<br>Travis Bradberry, M.S. and Josh Feder, M.D.   | 49  |
| Functional Emotional Developmental Questionnaire (FEDQ) for<br>Childhood: A Preliminary Report on the Questions and their Clinical Meaning—<br>Jacob Greenspan and Stanley I. Greenspan, M.D.   | 71  |
| Book Review: <u>Neurodevelopmental Disorders: Diagnosis and Treatment</u> —<br>Molly Romer Witten, Ph.D.  | 117 |

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# Journal of Developmental and Learning Disorders

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## EDITORIAL:

# A Developmental Model for Research on Interventions for Autistic Spectrum Disorders

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

Traditionally, autistic spectrum disorders (ASD) have been thought of in two ways. One is as a unitary syndrome with different types of “treatments” for the syndrome. The other is as a number of different (though related) developmental challenges, including auditory processing and language, motor planning and sequencing, visual-spatial processing, sensory modulation, and social and emotional relating and interacting at different functional emotional developmental levels. This way of conceptualizing ASD-type problems often involves a comprehensive intervention program that includes specific interventions for each of these developmental challenges (e.g., speech and language therapy, occupational therapy, work on relating, interacting, and social skills, etc.).

The developmental challenges that tend to fall under the ASD umbrella are reasonably well known. It is well established that children under the umbrella of ASD have severe auditory processing and language challenges. Some have circumscribed memory-based language capacities (repeating words or even whole books), but for the most part lack the ability to use language in an emotionally meaningful manner. It’s also well known that there are difficulties with social and emotional interaction and, in particular, long chains of back-and-forth, reciprocal affect signaling, imaginative play and thinking, empathy, and higher levels of reflective thinking (making inferences). Less well known, but equally prominent, are difficulties in motor planning and sequencing, i.e., the ability to carry out complex multi-step actions in a flexible and goal-directed manner. Also, prominent, but less well recognized, are difficulties with visual-spatial processing, i.e., the ability to think and problem-solve with spatial concepts. While many of the children have circumscribed strengths in aspects of visual memory (e.g., remembering a picture or the location of an object or a particular place), most children under the ASD umbrella have marked difficulties with visual-spatial thinking, which would include, for example, constructing a pretend city or transposing different block designs. In addition, it is widely recognized that children under the ASD umbrella have challenges with regulating or modulating sensations and tend to be either sensory over- or underreactive. In a study of 200

children who were diagnosed with autistic spectrum disorders, we found that the vast majority of children had marked difficulties in all of these areas (Greenspan & Wieder, 1997).

While there has been hope to find an identifiable cause or number of causes and related pathophysiologic pathways that explain ASD and lead to improved treatments, such hope has not yet been realized. In fact, neurobiological research supports the notion that ASD involves multiple developmental challenges and requires comprehensive treatment approaches which address each of these elements (e.g., finding multiple areas of the central nervous system involved in what's under the ASD umbrella) (Bauman, 2000).

Many comprehensive intervention programs also take this tack by including a variety of different therapies to address all the different challenges. Yet, in evaluating research, particularly intervention research, there has been a tendency to look at ASD as a unitary disorder with a unitary treatment. For example, in looking at behavioral approaches, there is a tendency to conceptualize an approach such as ABA as intervening with autistic spectrum disorders and as influencing certain essential features of the disorder, such as language, perseverative and self-stimulatory behaviors, and educational problems.

What would be the approach to evaluating research on interventions for ASD, if ASD were viewed as a series of related developmental challenges which require multiple, though coordinated, interventions? The approach would obviously involve systematically describing each of the developmental challenges to be addressed and then assessing the efficacy of available interventions for each of these challenges.

When we take such an approach, a very different picture emerges than when we take an approach based on the unproven assumption that ASD is a unitary disorder with a unitary treatment. For example, there is a great deal of evidence that a variety of dynamic, affect-based approaches that focus on social interactions can facilitate the abilities of children with ASD to relate and socially interact. There is also evidence supporting dynamic approaches for meaningful speech and language development. There is far more evidence favoring dynamic approaches than structured behavioral treatment for many of the most critical developmental challenges under the ASD umbrella (Tsakiris, 2000). Interestingly, in the latest replication studies, very structured (ABA) behavioral approaches only appear to significantly help about one third of the children with ASD and there are no clinical trial studies comparing ABA approaches with more dynamic, comprehensive ones (Smith, 2001). In addition, improvement in these studies is defined mostly in terms of limited and structured educational goals rather than the most essential defining characteristics of ASD. The essential defining characteristics of ASD include difficulties with affective reciprocity, intimate relating, creative and pragmatic use of language, and the capacity to make inferences, construct a theory of mind, and engage in high-level reflective thinking (Minshev & Goldstein, 2000).

A framework for research on interventions for ASD must, therefore, be based on an understanding of the different developmental challenges that are often described under the umbrella of ASD and focus on specific interventions and outcomes for

each of these challenges. In other words, each developmental challenge and each intervention must be properly assessed. This framework needs include a focus on those developmental challenges that are uniquely associated with ASD. For example, many children with a variety of developmental challenges have language problems. Children who are characterized under the ASD umbrella, however, have unique problems with the creative and reflective use of language (e.g., making inferences and constructing a theory of mind). A developmental framework for intervention research on ASD should therefore include the following components illustrated in the chart below.

#### **A Developmental Framework for Research on Interventions for ASD**

| <b><i>Developmental Challenges</i></b>   | <b><i>Interventions</i></b> | <b><i>Baseline Assessments</i></b> | <b><i>Outcome</i></b> |
|--|-----------------------------|------------------------------------|-----------------------|
| Auditory processing and language   |                             |                                    |                       |
| Motor planning and sequencing  |                             |                                    |                       |
| Visual-spatial processing  |                             |                                    |                       |
| Sensory modulation (hypo- or hyperreactivity)  |                             |                                    |                       |
| Emotional and social functioning (functional emotional developmental capacities)   |                             |                                    |                       |
| • Regulation & attention   |                             |                                    |                       |
| • Engaging & relating  |                             |                                    |                       |
| • Reciprocal (intentional) interactions with affects and gestures  |                             |                                    |                       |
| • Continuous flow of problem-solving social interactions   |                             |                                    |                       |
| • Imaginative emotionally-based use of ideas   |                             |                                    |                       |
| • Logical and reality-based organization of emotions and ideas   |                             |                                    |                       |
| • Higher levels of reflective thinking   |                             |                                    |                       |
| • Multi-causal comparative thinking  |                             |                                    |                       |
| • Gray-area, differentiated thinking   |                             |                                    |                       |
| • Thinking off an internal standard and sense of self, including the capacity to make inferences, truly empathize with others, and make social judgments |                             |                                    |                       |

Research on interventions for ASD needs to be based on the type of framework illustrated above. There are obviously different ways of conceptualizing the develop-

mental challenges and there will also, obviously, be different interventions for each of these challenges, as well as different recommendations for base-line assessment tools as well as outcomes. It is essential, however, to have such a detailed framework as a basis for conducting and evaluating intervention research.

Without such a framework, misleading assumptions tend to be made. For example, it may be assumed that an intervention is improving the disorder, when it is only working on one of the developmental challenges that are described under the umbrella of the disorder (e.g., memory-based language or structured educational goals). Furthermore, it is quite possible that when only selected challenges are worked with and baseline assessments and outcome measures only look at those challenges, other challenges, such as the capacity for relating with intimacy, being empathetic, engaging in reciprocal affective exchanges, etc., are actually getting worse. If the framework is not comprehensive and doesn't include outcome assessments in all of these areas, we have no way of knowing if, in fact, certain areas of functioning are deteriorating while a few selected ones that may be less central to the unique features that define ASD show modest improvement.

Therefore, just as it's critical in general medicine to have baseline and outcome assessments on a variety of agreed-upon physical parameters (e.g., liver functioning, kidney functioning, etc.), it is vital in intervention studies for developmental challenges to have an agreed-upon framework for what constitutes the different developmental challenges that are commonly described under the umbrella of the disorder. It's also necessary to have relevant baseline and outcome measures (as well as a clear description of the intervention) for each developmental challenge.

A chapter in the *Clinical Practice Guidelines: Redefining the Standards of Care for Infants, Children, and Families with Special Needs* (Tsakiris, 2000), reviews intervention research on ASD and related conditions from the perspective of each of the developmental challenges involved under the ASD umbrella. It also addresses specific interventions for each of these areas that together make up a comprehensive program. As mentioned above, looking at intervention research within this type of a framework, provides a fuller, more developmentally useful picture. More importantly, it provides a foundation for future research that can facilitate understanding of all the developmental challenges and interventions that need to be considered in working with children described under the ASD umbrella.

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# SPECIAL COMMENTARY:

## Early Factors in Development and the Identification of At Risk Patterns\*

**T. Berry Brazelton, M.D.**

What a revelation it was yesterday to see what DIR has done for this field, and how much hunger there was for this. Your approach, which values the strengths of the disordered child and allows for hope in the parents, is so reassuring. It made me go back to what I went through in the 1950's when I was working in child psychiatry and found it was another pathological model, like my training in pediatrics in which all we looked for was disorder or disease. Child psychiatry was like that too; it blamed the victim. At the Putnam Children's Center, which was a marvelous psychoanalytically oriented place, we blamed the victim. Yet, I could see that these children didn't look quite right at birth, they looked different, and they behaved differently, and I thought that as a pediatrician it was my duty to find out what was different about them. So, I began to look for ways to identify deviations in the newborn.

In 1955 we thought that babies couldn't see or hear. Where did we get such a stupid idea? But, I think it was really driven by a putdown for parents because every mother knows her baby can see or hear, every father knows it. So I went down to see Dr. Sally Provence at the Yale Child Study Center.

Dr. Sally Provence with a baby was like a ballet dancer, a "pas de deux", playing with this newborn baby, and I said, "Sally," because this baby was doing all these things I'd never seen before, "Sally, it's almost as if you have gotten inside that baby." And she said something absolutely memorable, she said, "Well, there's a baby inside of each of us. Can't we get inside the baby?"

It drove me to start collecting behaviors of the newborn, which now makes up the Neonatal Behavioral Assessment Scale (NBAS) (Brazelton & Nugent, 1995). I finally published it in 1973. The marvelous thing was that we have learned so much about newborns since then. The driving force was that I really wanted to share the newborn's behavior with mothers and fathers. It seemed to me that the newborn was

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\*These comments are adapted from a presentation given at the Annual ICDL Conference in McLean, Virginia on November 9, 2001.

ready to shape his or her own environment. I've become more and more convinced of that ever since. If we look at a baby's behavior over the years you will see how much that baby is shaping what goes on between him and the environment around him. If we don't, we are missing a major opportunity. Hence, my emphasis on using the baby's behavior as a language between parent and caregiver.

Best performance seemed absolutely critical to me. To get the baby to best would be what I think any parent would do. They would work very hard to give that baby the kind of protective environment it took, a kind of affective attunement. If you hold a baby in your hands and speak softly, "Hi, how you doing?" any newborn turns to your voice, finds your face and then arches towards you. And if you put the mother on one side and you are over here and both talk, any newborn (worth it's salt) chooses the female voice and turns to her. When it arches to her she automatically reaches for her baby, "You know me already." And if you compete with a father's voice, 80% of them choose their father's voice and for the other 20% I tip their head. At that point every father does the same thing! Every father grabs his baby from me and says, "You know me already!" Now, what are we doing in pediatrics or in child psychiatry if we don't use this sort of way to attract parents to their newborn?

When a child has been progressing through the first year, and "suddenly" makes a turn for the worse in the second year (as in autism), parents are overwhelmed and stricken. They see it as their failure, even though they have recognized deviance before. The parents by that time are loaded with guilt, loaded with passion gone astray. I wonder when it all could have been detected? When you go back with those mothers they can tell you, "I always knew something was wrong with my baby". If that is true shouldn't we start in the beginning and set up a relationship in which a mother dares to tell you little observations that she thinks herself crazy for thinking and give her the credit for wanting to identify deviance in her baby? With the United Cerebral Palsy Foundation statistics, if a mother refers her baby it's at five months. If a doctor refers the baby it's sixteen months. I think, as we heard this morning, we're losing valuable time not only for the baby but also for the whole family. By two years a mother has lost ground. She can be depressed and locked up so that she can't be available any longer. Could we do something earlier? I would like to present some of the things that we have learned from the newborn assessment.

### **Newborn Behavioral Assessment Scale (NBAS)**

We fought for best performance in the newborn. That meant that the examiner had to facilitate the baby all through the exam. Everybody said "Well how do you know when you get to best?" Doesn't any parent know when you get to best? I think we do. Then they said that nobody but Brazelton can do it. Well, that's just not true. We've trained hundreds of people all over the world to use the scale. What we haven't done very well yet, and I hope that we are doing better, is training them to share it with parents. That was the real goal for the assessment. It is not a score but a way of looking at an individual as an individual and sharing that individuality with

the parent. You are looking for the things the baby can do. I have never yet found a baby that was going to be difficult for parents, that I couldn't capture those parents right from the first. We can already become a team to deal with that difficulty. If I showed them the things that the baby could do first, then the parent was right with me and then I could say, "Now we have some things to work on." The mother sits up straight and with tears rolling down her face; she had already known everything I knew about the baby's problems. To not share it with her is deserting her. We share the problem behavior together. She is available for my intervention from the first.

## **Newborn Behavior**

Habituation is absolutely critical to a baby. Many of the babies that you are seeing are using avoidance as a way of habituating. They are working very hard to keep an overwhelming environment from inflicting itself on their hypersensitive neurological system. The kind of overloading that may show up as autistic-like behavior, the lidded eyes that go with this as they're trying to manage an environment that's overloading them. These attempts to shut out, as well as the startles or disorganized state behavior may point to an easily overloaded disorganized central nervous system.

Crack/cocaine exposed babies often cannot habituate to stimuli. When you look in their eyes they stop breathing. When you talk too loud they stop breathing. When you pick them up too fast they stop breathing. On the other hand, if you pick one up very quietly without looking at him, you'll feel him stiffen, arch, finally relax in your arms and you can look down at him. Then you feel the stiffening all over again and then finally relaxing, then you can talk and they stiffen and then finally you can talk and rock and hold and look. Now, what we've learned from those babies is to use one modality at a time. I think many of you as therapists are doing this with these disorganized children in therapy. I want to point out how critical this is to a nervous system that may be somewhat disordered. To give them a chance to pick up one modality, assimilate it, add another modality to it, assimilate it, then finally get all modalities together. Think of the learning that goes behind that!

I want to talk to you about a 31 week old premature baby who was born at 27 weeks, had an interventricular hemorrhage, respiratory distress syndrome. (Lester, et. al., 1997) He was finally off supports in the newborn nursery at 31 weeks so that we could play with him. The only evidence that you could see in this premature baby, at 31 weeks, was the difference in the color of his face and the rest of his body. Everybody, neonatologist, nurses, everybody else, thought uh-oh; this baby is going to be damaged. Think what these parents had been through in four weeks. Think of the grief work that they'd had to do over those four weeks. Now, they happened to be there when I was playing with this baby. But this baby had his hand up by his mouth as if to control his startles. Then when he started to move his color changes and then he throws himself over on his back. Now, his color improves, but his heart rate which had been pretty high, was already by this time at its absolute peak. Then

he throws off a tonic neck reflex; he uses it and brings his hand up to his mouth. He begins to get reorganized. By now his heart rate is down again. His autonomic system is already complying with the motor system and he brings his legs over and crosses them. We wrap him up and start to play with him. Because this baby calmed himself down at 31 weeks he would do what we asked him to do. He follows my face back and forth. And then what does he do? He says, "I've had enough." We have 11 of these behaviors which say "I've had enough, leave me alone." How do we teach parents about these behaviors so they respect the baby's hypersensitivity? How often do we send these babies, who have fought their way through all of these traumas, home to an environment, which has no concept of overloading a disorganized nervous system? (Als & Brazelton, 1979). And they are blamed for his disorganization.

We did a study after this of 30 premature babies, (Lester, et. al., 1987) all under 29 weeks at birth who went through interventricular hemorrhages, respiratory distress, problems of immaturity, and we gave them a risk rating. The risk rating did not predict to their outcome at 18 months, cognitive outcome, unless you tied it to their socioeconomic status, to the availability of the environment. It doesn't surprise any of us but the socioeconomic status predicted with a .65. If you took the neurological at 40 weeks it predicted poorly something like .2. But .65 from socioeconomic status coupled with the neonatal assessment at 40 weeks predicted with a .85 to outcome to 18 months. I think what it's telling us is that the parents can take what we can show them about the baby to improve their outcome. We can model for them how to handle these babies to make a significant difference in these babies future. It was a revelation to hear your sensitive and parent-shared approach. To hear you talk about how you used these childrens' behavior to reach out for parents. (Als & Brazelton, 1979)

Let me tell you about another group of babies that we looked at. (Als, et. al., 1976) This baby was born at 40 weeks, weighed 6-lb. 3 oz. and was one in a study that you have in your notebook called Underweight for Age. This baby was not underweight for age unless you used the Ponderal Index, which is a relationship of length to weight. This baby then was below the tenth percentile and showed mild intrauterine deprivation. We had no way of accounting for the deprivation. We couldn't have predicted it nor could the obstetrician because there was no precursor to tell us that this mother might have a baby whom was undernourished in the uterus. But, at birth, the baby, with this long, skinny body, had this worried look on his face. That worried look ought to be a predictor. When you pick him up he already starts to look worried. If you play with him he begins to throw off startles, begins to look like he might have problems. He will either throw up, have a BM, start hiccupping, or demonstrate other ways of shutting you out. These newborns are treated in the normal nursery, as normal newborns and sent home to parents as normal. They were predictable as crying for the next 3-4 months for something like 8-10 hours a day. And the crying was not the kind of normal colic; this was incisive and painful to hear. Parents couldn't stop it. They'd only add to it. Many parents might abuse a child like that when she couldn't do anything for him. The more she did, of course, the more the baby cried. This is indicating a hypersensitive nervous system. When you over-

load a central nervous system like this there are only a few ways a neonate can handle it. Either by using habituation or becoming hyperactive or by crying so they can shut out the environment. Without those they couldn't manage to keep their autonomic and motor systems under control. (Brazelton, et. al., 1977).

So, I would be looking for the threshold for taking in and utilizing information with children that you are working with. The threshold that gets overloaded, what does the child do? I would think a baby that looks like he really can't take in and respond to stimuli was telling you something. Babies who can habituate can have that alert state. Without one you don't get the other. And so, I would think that the predictions would be poor state control. You could look at how well the baby slept, how well it was able to shut out the environment and still wake up to respond, and I would think those would become important as predictors to disordered babies.

Let me tell you about a baby that we saw in our research. This baby had a hare lip and cleft palet. It was so severe that any time he would get excited about fixing on anything in the environment, like a red ball or a soft rattle or your face, the baby would choke, startle and have to pull away. He had so many secretions he couldn't handle them. Survival took over from his desire to fix on and follow these objects that we were offering him. When the mother came in at 6 weeks she looked just like the baby and we thought, "She's having a real grief reaction." And then she started breathing just like the baby and we thought, "She needs a lot of help." And all of a sudden, we realized what she was doing. She was helping that baby through every overload and pulling him back down so that instead of losing control at every peak, he could get himself back by modeling on the mother. I think for a mother to be able to use that kind of identification in her grief work, to model it for the baby, and to anticipate what it would do for the baby deserves all of our respect. (Brazelton, et. al., 1974, Brazelton, et. al., 1977)

If we translate this passion into parent's awareness of a baby with PDD, I guess my question is, can we begin to pick up small cues in their behavior very much earlier? We call it the Touchpoints model at each stage of development using the baby's behavior with an open ear. The mother might say, "This baby isn't quite doing what I expected her to," or, "She isn't just like my other kids." We need to respect what she is trying to say to us. Otherwise we must wait until there is a real break in the child's functioning before we can make the diagnosis of PDD.

Here is an example of using our modeling to help. Marcy was a totally blind baby who had one sightless globe and a distorted looking face. (Als, et. al., 1980) The mother was a lawyer and the father was a judge so these were sophisticated people. They knew all the literature about genetic disorders, so when I went to see Marcy at three days I heard that Marcy's mother hasn't been willing to see her. She was advised not to see her because she might suffer too much. So I took Marcy out to see this woman in her room. I picked Marcy up, and I could feel her stiffen, and I said, "Uh oh, she is hypersensitive." If one modality is knocked out, the others are almost always hypersensitive. I waited until she quieted down and then I said, "Hi, Marcy. Hi, Marcy. How are you doing, Marcy?" Lowering my voice, slowing it down, paying attention to her hypersensitive threshold. As I did this Marcy began to turn her

head toward me and arch toward me. At that point Marcy's mother said, "My God, she's a baby after all." Who could blame that mother? In her crib, at 5 months Marcy reached for a toy and found it by herself. She continued to be hypersensitive but organized in the auditory, tactile, and kinesthetic areas. Her mother had worked so hard. We had to model the way to deal with her hypersensitivity for the mother at each stage of development, but she was ready. She was hungry for it. Well, at 9 months Marcy was lying in her crib going "Aaaahhhh" and rotating her hand in "autisms". My researchers thought that she was going to be autistic. I asked what her mother thought. Her mother thought she was going to use this behavior. At 12 months Marcy got up and started walking going "Ah, ah, ah, ah." She never touched a piece of furniture; she walked through doors without touching them. She'd started her radar three months before she needed it. What kind of programming are we dealing with in the human infant that gives us that kind of predictive mapping of behavior? Marcy is about 8 or 9 now, and is in a school in Brookline doing very well with Braille. But, Marcy's mother is a remarkable lady and Marcy is a remarkable little girl. (Als, et. al., 1980)

We must start early. We need to be sensitive to early cues of an easily disorganized nervous system: poor state control, shooting from sleeping to crying and irritability, an easily overloaded nervous system, parent's observation of a baby "who's different." Parents must become our windows into babies' disorganization. Their understanding of this behavior is critical to the babies' ability to overcome it. (Brazelton, 1992)

"For in the newborn baby is the future of our world. A mother should hold that baby close so that he knows the world is his. The father should take that baby to the highest hill and show him how wide and wonderful his world is."

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# Reflexes Gone Astray in Autism in Infancy

**Philip Teitelbaum, Osnat B. Teitelbaum, Joshua Fryman, and Ralph Maurer**

**Abstract.** *In the cases presented in this paper plus others we hypothesize that movement disturbances in infants can be interpreted as reflexes gone astray and may be early indicators for a diagnosis of autism. In the children reviewed some reflexes persist too long in infancy, whereas others first appear much later than they should. The asymmetrical tonic neck reflex is one reflex that may persist too long in autism. Head-verticalization in response to body tilt is a reflex that does not appear when it should in a subgroup of autistic-to-be infants. We suggest that it may be used by pediatricians to quickly screen for such autistic-to-be children, especially in families where there is a history of autism.*

## **Introduction**

In our earlier work (Teitelbaum, 1998) we showed that infants destined to become autistic showed a characteristic cluster of disturbances in movement patterns detectable by our methods at 4-6 months of age. To do this, we used Eshkol-Wachman Movement Analysis (EWMN) (Eshkol, 1958) in conjunction with laser disc still-frame analysis. Through the cases presented plus others we suggest that the movement disturbances in infancy in autism can be understood as reflexes gone astray in infancy. In the present paper, we will re-analyze some of these movement disturbances in terms of infantile reflexes.

## **Background**

We asked parents of autistic children (diagnosed by conventional methods usually at 3 years or older) to send us videos of their children taken when they were infants. We advertised in the monthly periodical published by the National Committee on Autism and in the e-mail list run by the Autism Society of America. We received and copied videos of 17 such infants and compared their patterns of lying (prone and supine), righting from their back to their stomach, sitting, crawling, standing, and walking with that of 15 typically developing infants. Selected portions of these behaviors were transferred to digital video discs and analyzed using EWMN. This is a universal movement language utilizing the concept of the body as a linkage

of axes, a spherical system of reference, and the idea of axes of movement. Based on this foundation, a distinction can be made between which segments are actively moving versus those that are being carried passively along. Thus, a deeper understanding of abnormal movement is possible.

## Results and Discussion

We believe that movement disturbances in autism and Asperger's syndrome are related to the sequential development of infantile reflexes. Below we briefly present a few examples of these cases.

(a) **Asymmetrical Tonic Neck Reflex:** An Asperger's-to-be infant of 8 months of age was lying on its back with left arm outstretched, with its head turned toward the outstretched arm. Normally, when a child of this age turns over, it will turn in the direction in which the head is turned, i.e. toward its left. However, in this instance, the child turned to the right, opposite in direction from that to which its head was facing. The child did so by arching its back, thus decreasing the contact with the ground to only heels and head (bridge position) (figure 2). Using the outstretched arm as a lever, it was lifted straight up, making a full arc of 180 degrees to the child's right. As the arm was lifted, the head and eyes maintained their fixed orientation to the outstretched arm, the head turning to the right as the arm did so (figure 3). As the arm completed its trajectory to the right, the shoulders and torso followed, so that the child's body turned over the full 180 degrees to the right (figure 4). This child's twin sister, who was diagnosed with Asperger's syndrome, showed the same pattern of righting.

This phenomenon was puzzling until we realized that the original posture of outstretched arm with the fixed relation of the head to it was actually the asymmetrical tonic neck reflex pattern (Payne, et al 1964). In a typically developing child, the asymmetrical tonic neck reflex is present very early in its development, from birth till about 4 months of age (Peiper, 1962, Paine, et al 1964 and see figure 5). Therefore, it is abnormal for it still to be evident in a child of 8 months of age. So in these Asperger's-to-be infants, one abnormality was that the asymmetrical tonic neck reflex persisted too long in the child's neural development, and it interfered with the expression of the normal cephalocaudal pattern of righting that should have been evident as early as six months of age.

In another autistic child we studied we found that at 11 months of age the child was beginning to stand and walk. In this child also, the asymmetrical tonic neck reflex was still present so that the child overbalanced and fell in the direction of the outstretched arm. Therefore, even as late as 11 months old, the asymmetrical tonic neck reflex had not yet been inhibited, causing the child to fall while trying to walk. This leads us to believe that one abnormality that can be seen in infancy in autism and in Asperger's syndrome is excessively long persistence of some reflexes that should have been inhibited earlier in the child's development.

(b) **Protective Reflexes:** Another finding from our study is that some reflexes in autistic children that should have appeared by a certain age have not done so. As described earlier by our group, three autistic children of around 8 months of age fell from a sitting position forwards, backwards, or to the side without putting out their arms and dorsiflexing their head to protect it as they fell, the way a typically developing child of that age would do.

This indicates that protective reflexes of the arms and head are absent in these children, at an age when they should be present. (One mother of an Asperger's child reported to us that even when her child was in his teens, he would walk or run into walls without lifting up his arms to protect himself).

(c) **Head-Verticalization Reflex:** Another such reflex (whose appearance in infancy is delayed, sometimes for many years) is the head-verticalization reflex (Peiper, 1962). This is easily elicited in a typically developing infant at 6-8 months of age:

Simply hold the child in the air around the waist facing the video camera. Then tilt the child's body SLOWLY around 45 degrees to one side, then SLOWLY back to the erect vertical position, and then SLOWLY to the other side.

A typically developing child will maintain its head vertical as the body is being tilted, indicating that based on the vestibular signal that is generated during the body tilt, the head is compensating for the tilt by moving itself simultaneously in the direction opposite to the tilt, thus maintaining itself in the vertical position (figure 6). In a number of autistic children, the head did not compensate for the tilt, thus keeping itself in line with the midline of the body rather than with the absolute vertical. Such a lack of compensation implies that the parts of the brain involved in the integration of such reflexes, and their appearance and disappearance during development are damaged. We have seen an absence of head-verticalization in autistic children as old as 7 years. Thus, not only is this reflex absent in infancy but it may be delayed in its appearance for some years. The primate animal model of autism that has been proposed (Teitelbaum, et al 2002) should display a similar aberrant integration of reflexes in infancy. This primate model should allow us to explore the brain areas that are involved in the integration of such reflexes in infancy. The role of these areas in thought, social behavior, and communication should also be susceptible of exploration in such an animal model. It should be noted that because language and intellect are typically intact in Asperger's syndrome, it is difficult to diagnose, and is usually not diagnosed until 6 years of age, or even much later. The present paper hypothesizes that by studying the movements of such children in infancy, Asperger's syndrome may be diagnosed as a form of autism as early as 6 months of age. The differential diagnosis can be confirmed by the development of normal language in the next few months.

It is axiomatic that the earlier that therapy is applied, the better the outcome. Therefore, the fact that diagnosis of autism and Asperger's syndrome may be possible so early in infancy suggests that earlier forms of therapy appropriate for autistic, and perhaps somewhat different therapies for Asperger's infants, should be developed for infants who display such movement disturbances.

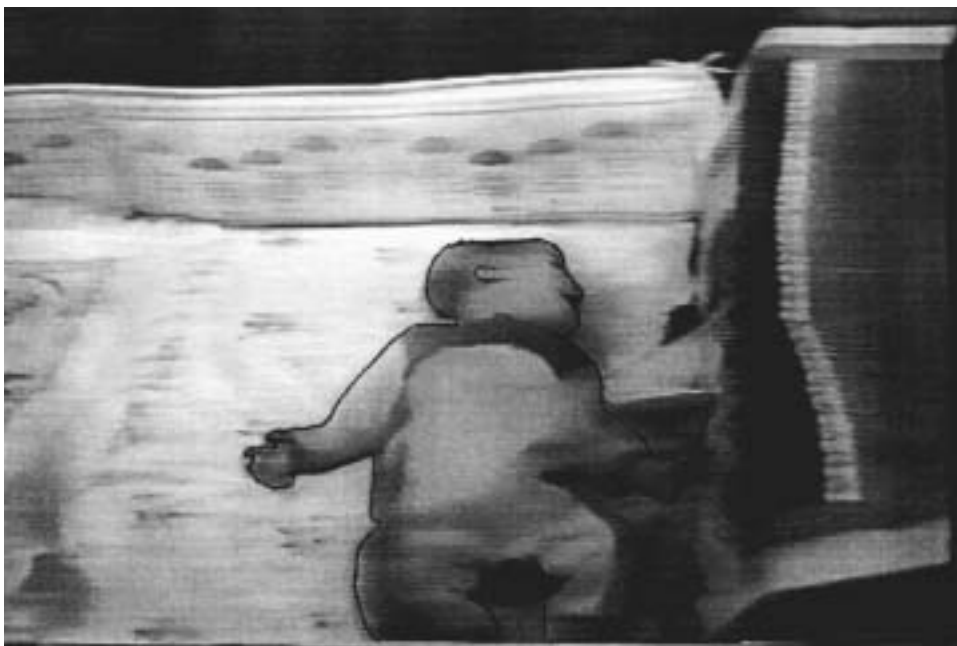
**Figure Legends**

FIGURE 1. An 8-month old Asperger's infant is lying with its head facing its own left. In a normal infant, this would signal turning over to its left, if such a turn were to occur.

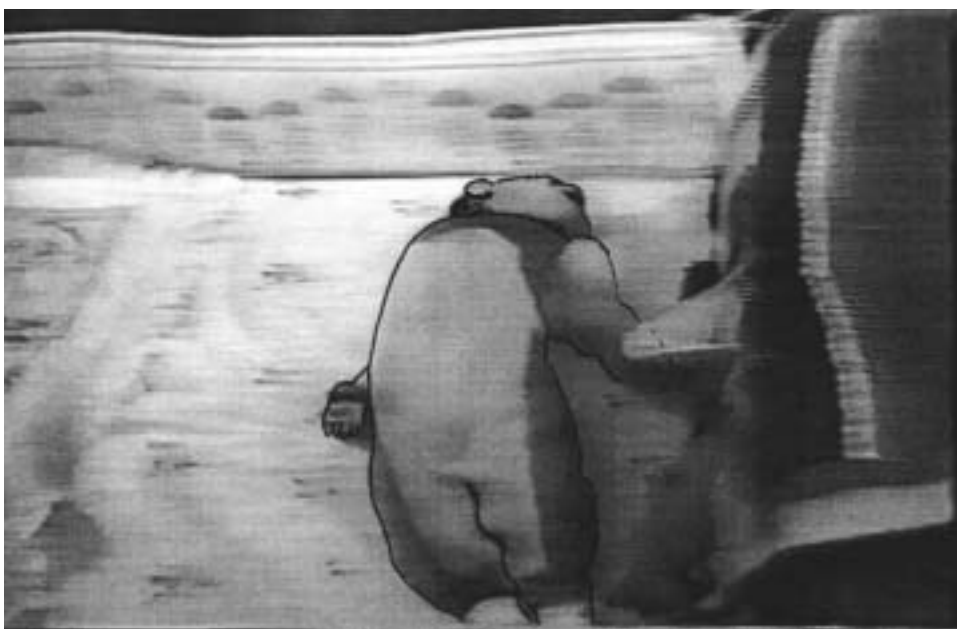


FIGURE 2. The Asperger's infant arches its back, in preparation for turning over.

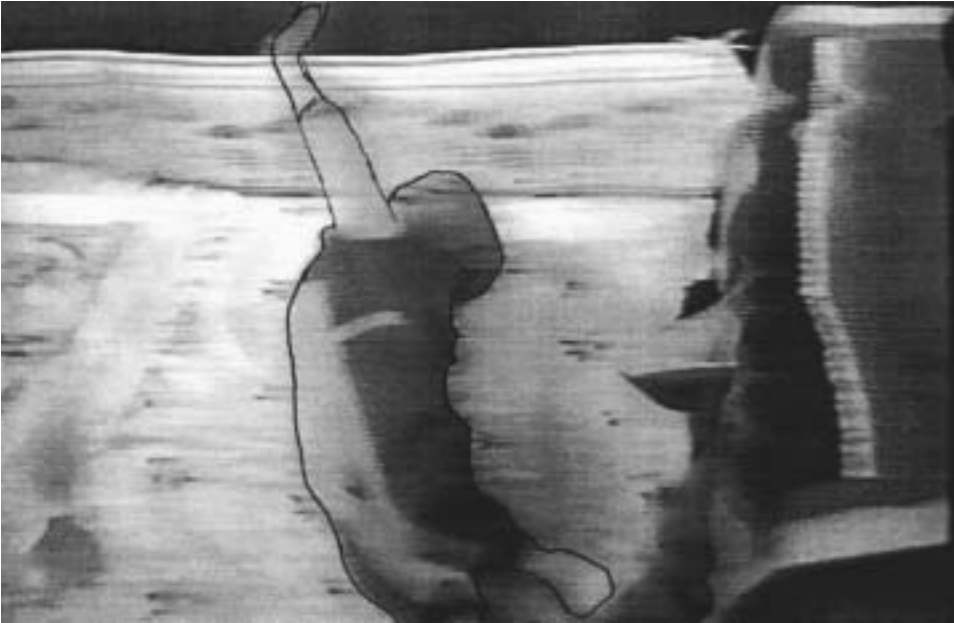


FIGURE 3. The infant swings its extended arm upward and towards its own right. The head and eyes are locked to the arm during the asymmetrical tonic neck reflex, so the head and body turn over in the direction in which the arm is swinging: i.e., in the “wrong” direction, according to the direction in which the head was turned at the beginning of this reflex sequence.



FIGURE 4. The infant has fallen over onto its stomach, the left arm still in the extended position.



FIGURE 5. A normal baby showing the asymmetrical tonic neck reflex.



FIGURE 6.(top) The “tilting test” in a normal six month old baby. The head and body are held in the vertical position. (bottom) The child’s body is slowly tilted about 45 degrees to the child’s right. The child maintains its head in the absolute vertical, rather than remaining in line with the mid-line axis of the body. The slow tilt is then repeated toward the other side, and the normal baby will again maintain its head in the vertical. In a sub-group of autistic children, the head remains in line with the mid-line axis of the tilted body, rather than orienting itself to the absolute vertical, on one or both sides of body tilt.

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# DIFFERENCES IN AFFECT CUING: A Window for the Identification of Risk Patterns for Autism Spectrum Disorders in the First Year of Life

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D.Phil.**

There is great interest in identifying children at risk of developing Autism Spectrum Disorder (ASD) at earlier ages in order to enhance the opportunity for early intervention as well as to understand the early stages of this disorder in the context of the search for neurobiological correlates and preventative strategies. Recent research suggests that an early sign of the developmental trajectory leading to ASD is a deficit that appears in infants around the age of 9 months in their capacity for reciprocal exchanges of emotional expressions. In these exchanges of affect, an impairment can be observed in the detail and complexity of the facial expressions of emotion, as well as a discord between the infant's movements in response to her caregiver's vocalizations, facial expressions, and gestures. In our study we are seeking to develop a systematic procedure for looking at the dynamic process of co-regulated facial expressions of affect and the rhythmicity of the infant's movements as a tool for identifying 9 month-old infants that are at risk of developing ASD. To develop such a tool we are capitalizing on recent developments in the dynamic systems theory (DST) analysis of facial expressions.

On the standard affect program theory (APT), there are said to be a limited number of basic emotions (e.g. interest, surprise, happiness, sadness, anger, fear) that are indexed by stereotypical facial expressions. The production of these facial expressions and the responses they evoke are thought to be controlled by genetically determined programs (Ekman 1980). The occurrence of an emotion is then seen as a composite form of reflex: a stimulus triggers a neural program that controls a neuromuscular/expressive, autonomic, behavioral, and experiential sequence of events (see Griffiths 1997).

On this paradigm, one studies the facial expressions that index basic emotions by isolating a movement in a single region of the face, or combinations of regional movements. The researcher focuses on one member of the dyad at a time.

Transitional points (say, from one facial expression to another) are treated as markers which frame when episodes begin/end.

As fruitful as this approach has been in the analysis of adult facial expressions, it has proved to be somewhat difficult to implement in the analysis of facial expressions in young infants prior to the age of 18 months. One problem is that stable, ‘stereotypical’ facial expressions often do not appear until 18 months. Another problem is that the resting tonus of the facial muscles changes with changes in the state of alertness, which are more frequent and unpredictable in infants. It can also be difficult to determine specific facial actions in young infants when many actions are occurring simultaneously (i.e. when there is a “noisy” background). And finally, some facial actions are slow in onset and offset, and the lightness of facial hair and less visible wrinkles can make it difficult to distinguish these facial actions from a baseline set of features.

Perhaps the single most important reason, however, why dynamic systems theorists are seeking to refine the tools that we use to study facial expressions of affect in young infants, is that **facial expressions of emotion are constantly changing in response to the changing dynamics of social interactions**. Moreover, the stereotypical facial expressions associated with ‘basic’ emotions **develop** within the context of shared emotional experiences. For example, ‘Duchenne’ smiles are cited by affect program theorists as a paradigm of an innate communicative signal (Ekman 1979). Messinger, Fogel and Dickson’s micro-analysis of the emergence of ‘Duchenne’ smiles in a normal young infant revealed that:

- sometimes the smile only occurs on one side of the face or is stronger on one side
- sometimes the smile contains negative elements (e.g. grimaces)
- smiles are fleeting and change in response to equally swift reactions on the mother’s part. Out of this fast-paced interactional matrix more stable, recognizable expressions develop (Messinger, Fogel & Dickson 1997).

Thus, on the DST approach, one studies the complexity, detail, and responsiveness of subjects’ changing facial expressions of affect in the context of co-regulated interactions. Transitional points are seen as key events in their own right. Building on the literature that exists (e.g. on facial expressions, affect attunement and mirroring, intermodal attunement, synchrony, intersubjectivity, parental sensitivity), DST looks at the dyad as a whole: on how both partners are continuously interacting with and changing in respect to one another and aggregate patterns emerge from mutual co-action.

The shift to a DST approach has been an important, albeit implicit development in the study of autism. Using similar tools to those being developed by DST theorists, researchers in the field of ASD have established that:

- Children with ASD express less emotion overall (Yirmiya et al. 1989)
- Less positive emotion (Snow et al., 1987; Kasari et al., 1990; David & Tager-Flusberg 1997)

- More negative and neutral emotion (Bieberich & Morgan 1998; Krzeminska 2001)
- Display atypical facial expressions of positive emotion, marked by:
  - asymmetry
  - reduced movements in eye and mouth regions
  - shorter duration
  - highly labile
  - less intensity (Loveland et al. 1994)

Researchers in the field of ASD have also identified a number of ways in which deficits in facial expressions of affect in children at risk of developing ASD may interfere in their interactions with their caregivers:

- This may undermine the development of intersubjectivity (Hobson 1986; 1989)
- This may impair the caregiver's responsiveness to the child, thereby further undermining co-regulated affective interactions (Dawson et al. 1990)
- This may interfere with opportunities for the caregiver to imitate and enhance infant's facial expressions, which may further impair infant's affective development (Malatesta & Izard 1984)
- This may impair the shared gaze interactions needed for affective development (Mundy & Sigman 1989)

In the initial pilot phase of our research we examined the videotapes of 20 children between the ages of 11 months and 6 years, all of whom had been diagnosed with ASD. In most cases the diagnosis occurred after the time of the filming. What we have seen so far in our analysis of these tapes is that:

- Whereas a child who is developing typically displays continuous changes in her facial expressions of affect when interacting with her caregivers, young children with ASD display impairments in their reciprocal responsiveness
- Unlike a typical child whose smiles change in response to her caregiver's, the facial expressions of a child with ASD are largely unaffected by his caregiver's facial expressions
- Unlike a typical child whose transitions from flat to animated face or from one facial expression to another proceeds through stages, the transitions from flat to animated or from one facial expression to another are abrupt in the child with ASD
- The facial expressions of the child with ASD fail to match the variety or shifts in the caregiver's facial expressions
- In addition, there is an impairment in the rhythmicity of the child's movements and vocalizations in response to their caregiver's movements, vocalizations, facial expressions, and gestures.

Our goal in our research, therefore, is to ascertain whether these deficits in affective interactive behaviours are apparent in infants as young as 9 months who are at risk of developing ASD. Unlike studies that seek to establish whether infants exhibit

stereotypical facial expressions in situations designed to elicit basic emotional responses, we are working on developing a tool that assesses how the child engages in reciprocal affective gesturing in a continuous way. The procedure we are working on contains four components:

1. The first measures the degree of affective reciprocity: i.e. the duration and affective range of continuous communicative exchanges.
2. The second measures the detail and complexity of the infant's facial expressions of affect.
3. The third measures the degree to which facial expressions of affect change as a product of dynamic interaction.
4. The fourth measures the rhythm of the infant's movements and vocalizations in response to the caregiver's movements, vocalizations, facial expressions, and gestures.

In addition to the above measures, we are looking closely at the **rhythmicity** of the dyad's interactions. **Dyadic rhythmicity** is defined in terms of the tempo of interactive behaviours, body movements, and affective markers and the maintenance of that tempo across time. The four primary behavioural variables that we are looking at are:

- gestures,
- facial expressions,
- vocalizations/utterances,
- and head/eye/limb/hand/foot/trunk movements

As opposed to measuring the synchronicity of the behaviours (where B must respond to an action by A in some pre-defined unit of time, generally 1/3–1/5th of a second) the emphasis in the measurement of rhythmicity is on whether or not there is a steady beat and consistency in B's response to A's actions. There might, for example, be a latency of 2 seconds before B responds to A, but if B responds consistently to A and these responses are consistently close to 2 seconds this interaction is deemed rhythmic. It is also important to note that B's responses to A can be inter-modal: that is, rhythmicity is distinct from affect mirroring or attunement, where B responds to, e.g., a positive facial expression by A with a positive facial expression; B might respond to a positive facial expression with a gesture or a vocalization.

Initial testing of these measures on young children already diagnosed with ASD has been promising. In addition to seeing a marked arrhythmicity in their behaviours, we have observed a consistent pattern of deficits in their facial expressions of affect. Typically, these children display asymmetrical facial expressions of affect, from low to medium intensity, with a marked lack of complexity, and of limited duration. Most striking of all is how their transitions from a null face to a facial expression of affect, or from one facial expression to another, are generally extremely abrupt. It often feels as if there were some sort of internal switch that is suddenly turned on and just as suddenly turned off. In the next stage of our study, we will examine 9 month-old infants from an ultra high-risk population to ascertain whether similar deficits can be observed.

In early testing of this tool the above pattern has distinctly emerged. The following three subjects present a highly typical example of this pattern:

**#1. B.**

In this first case the child is a 5 <sup>3</sup>/<sub>4</sub> year-old male. In the video he is sitting in his mother's lap while interacting with his therapist. The tape can be divided into four 'episodes'. In the first, B. is completely unresponsive and remains so for some time, despite the strenuous efforts of his mother and therapist to engage his interest. His facial affect is completely flat and there is a dull listless look in his eyes. During this time the mother is continually whispering in his ear, which finally produces a muted facial expression of pleasure. The therapist then persuades the child to tell him a joke, which produces the second facial expression. The therapist then tells his own joke, which produces the third facial expression. And the mother then persuades B. to show the therapist how he dances, at which point the boy becomes more animated and begins to move his arms and legs in a jerky fashion: what we would describe as arrhythmic, according to the definition outlined above. (Arms and legs all move out of time with each other and there is no steady beat or consistency in these movements.) Using Ekman's FACS to code his facial expressions reveals the following patterns:

- i. 6 + 12X → 12Y + 25
  - 6: *Cheek Raiser & Lid Compressor* (Raise cheeks and compress lids)
  - 12Y: *Lip Corner Puller* (Medium intensity smile)
  - 25: *Lips Part* (Lips parted, jaw static, and teeth together)
  - Asymmetrical (left side dominant)
- ii. FA → 12X + 26
  - FA: Flat Affect
  - 12X: *Lip Corner Puller* (Low intensity smile)
  - 26: *Jaw Drop* (Lips together, jaw open, and teeth parted)
  - Asymmetrical (left side dominant)
- iii. 12X
  - 12X: *Lip Corner Puller* (Low intensity smile)
  - Symmetrical
- iv. 6 + 12Y + 26
  - 6: *Cheek Raiser & Lid Compressor* (Raise cheeks and compress lids)
  - 12Y: *Lip Corner Puller* (Medium intensity smile)
  - 26: *Jaw Drop* (Lips together, jaw open, and teeth parted)
5. Asymmetrical (left side dominant)

The data here tell a fascinating story all of their own. What is most striking about this coding is how the child's transitions from flat affect to smile are quite sudden; his facial expressions of pleasure are always in the range of low to medium intensity; his

smiles lack complexity and rarely involve the upper part of his face (the area around his eyes); and there is a marked 'left-right' asymmetry in his smiles, producing what appears to be a 'sly grin' rather than a fully developed and spreading smile. The very fact that we can speak of the child's "first facial expression," his "second facial expression," etc., is itself an indicator of how atypical his facial affective signalling is from what would typically be observed in a boy of his age in such a situation.

### **#2. A.**

A. is an 11 month-old girl. There is a good full-frontal view of her throughout the video. She is sitting passively in a baby-seat while her caregiver plays energetically with a doll immediately in front of her. Her facial affect is completely flat and she does not move her body or limbs at all during the interaction. After approximately a minute the caregiver begins to engage her interest. A. slowly begins to smile, but as the coding below demonstrates, it is a low intensity smile with very little complexity and a pronounced left-right asymmetry. Once again we see a very sudden transition in facial affect which occurs while the caregiver is still energetically playing with the doll.

12X + 26

→ 12X: *Lip Corner Puller* (Low intensity smile)

- Asymmetrical (right side dominant)
- transition: on → off

Virtually the same identical sequence is repeated two more times on the tape: i.e. there are two more 'episodes' (two more facial expressions of affect) with identical coding.

### **#3. A. 3 1/4 years old**

A. is a 3 1/4 year-old male. In the video he is playing in a stereotypical manner with a toy truck while his father sits off to one side trying to engage his attention. Upon prodding from the therapist to become playfully obstructive the father uses his hands to block the movement of the truck. At first A. simply ignores these intrusions but as the father becomes much more vocal and begins to gesture more animatedly A. suddenly smiles. Once again the pattern is the same: the smile is low intensity, shows little complexity, and is asymmetrical. There is also a marked asymmetry between A.'s body movements and those of his father. Even during the brief interlude where they interact, their movements display a markedly different tempo.

12X + 26

- Asymmetrical (Right side dominance)
- Low intensity
- Transition: on → off

In each of these cases there is a marked impairment in the detail, symmetry, and complexity of the child's facial expressions of emotion. Also striking is how limited the range of facial expressions are. In the 20 tapes that we have examined, we have only observed transitions from flat affect to smiling. To be sure, the nature of the interactions was such (all of the encounters took place within a therapeutic context) that there were no occasions to elicit a fear or anger response. Yet conspicuously missing were any signs of interest, curiosity or surprise, even though the caregivers were producing such facial expressions in a noticeably exaggerated manner.

In the next stage of our research we will investigate whether these deficits in reciprocal affective gesturing and motor-mediated complexity and detail of facial expressions of affect are present in 9 month-old infants that are thought to be at high risk of developing ASD. If these deficits are indeed confirmed it will create an opportunity for a host of new studies exploring the neurobiological correlates of these two fundamental processes that are impaired in the early development of ASD. At present, the search for neurobiological correlates is confounded by what are likely mainly secondary features of ASD which emerge later in development due to a long period of impaired social communication. The neurobiological processes underlying deficits in affective reciprocity and motor-mediated facial expressiveness may provide important clues as to both the underlying aetiology and pathophysiology of this complex disorder. It will be of special interest to observe if impairments in these two processes in a subtle form identify children who are vulnerable to later regression, as well as children who evidence early onset of the disorder. If, as we suspect, it identifies the group that is vulnerable to regression, an especially important future study would be to reduce various types of neurobiological stress on these children that may precipitate the regression.

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# TOUCHPOINTS AND DIR:

## Common Ground

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**ABSTRACT:** *Touchpoints and the DIR approach to children with developmental disorders affecting relating and communication are approaches to development that may have the potential to magnify each other's range of impact. DIR extends a humanistic understanding of emotional development to therapeutic interventions, while Touchpoints makes use of a systems theory approach to child development to support parent development and parent-provider relationships. DIR focuses on child development and parents' role in facilitating the emotional development of children with developmental disorders affecting relating and communication, while Touchpoints looks as well at the role of a child's development on parental development. Parent and child development are seen as mutually driving each other. This view embraces development as a process, and celebrates the fits and starts, the lurches ahead and the backward regressions. This is one of several ways in which this view of development may be harmonious with the DIR approach. It represents a shift from a focus on milestones towards an understanding of the movement along the way, the fits and starts, the circles and cycles, the connections and balances. One of the important revelations of the DIR model is that it sets forth a process: wherever a child is in the process is to be valued, and is not measured chronologically. It is central to this approach to move beyond dichotomous categories of negative and positive, and to accept regression as necessary, as serving a purpose. This "way of understanding" entails a paradigm shift: development is understood and appreciated as nonlinear and multidimensional. Healthcare professionals make this appreciation available to the families they serve, focusing on strengths rather than negatives, abandon prescriptive practices in favor of a collaborative approach, and shift from "objective" involvement to empathic involvement, empowering parents - and their children.*

Touchpoints and the DIR (Developmental, Individual Differences, Relationship-Based) approach to children with developmental disorders affecting relating and communication are overlapping approaches to development that may have the potential to magnify each other's range of impact. DIR extends a carefully reasoned and profoundly humanistic understanding of emotional development to therapeutic

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interventions with children with developmental disorders affecting relating and communication, while Touchpoints makes use of a systems theory approach to child development to support parent development and parent-provider relationships. DIR focuses on child development and parents' role in facilitating the emotional development of children with developmental disorders affecting relating and communication, while Touchpoints looks as well at the role of a child's development on parental development. In the following I will point to a few of the areas where common ground may be found, in the hope of spurring on further dialogue between the two approaches.

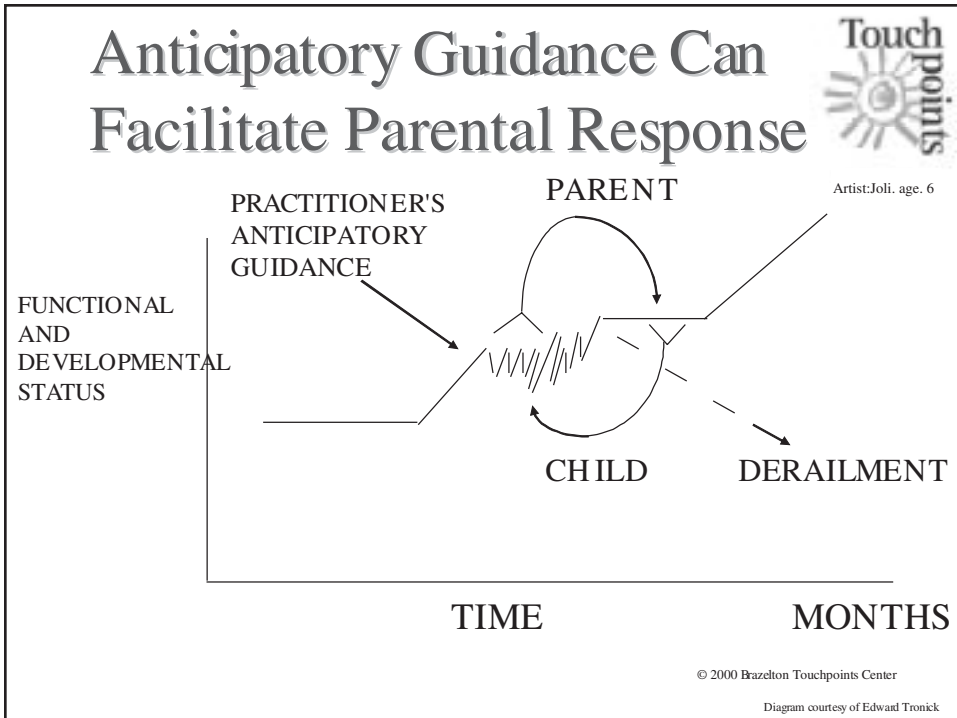
The Touchpoints model originated from clinical experience with a largely culturally homogenous population, and also primarily with, for lack of a better term, a "typically developing" population. Many, though, have pointed out the need for an adaptation of this model to families with children with special needs. Perhaps one day we will no longer make distinctions along current lines, and all children will be recognized as individual, and special. In the meantime, the Touchpoints approach can only stand to benefit from efforts to expand it to comprehend change in children with developmental disabilities, as well as in children from different cultures.

Touchpoints is derived from Dr. T. Berry Brazelton's fifty years in pediatric practice and the clinical "nuggets", as he calls them, that more than twenty five thousand patients have brought him. But what is Touchpoints? A set of techniques? A body of knowledge? A collection of clinical pearls? Is it a religion or a cult, or a new way of saying what is already widely held to be common sense? Perhaps it is a philosophy, as the DIR approach to children with developmental disorders affecting relating and communication is sometimes referred to, or a 'way of knowing' about change.

Touchpoints is a "way of knowing" about child and parent development that allows healthcare practitioners to reflect on and enhance their relationships with the families they work with. The relationship-altering component of this way of knowing is its use of systems theory to understand change. Parent and child development are seen as mutually driving each other. Winnicott's notion that the child does not exist without the parent is here folded back on itself to include the understanding that the parent does not exist without the child. But the practitioner, too, is seen as a part of a system that makes little sense if its components are scrutinized in isolation.

An early observation derived from the clinical "nuggets" is that development is non-linear. Discontinuous, and not even necessarily hierarchical, development is multi-dimensional, and characterized by regressions, bursts and pauses. This non-linear, non-hierarchical understanding of child and parent development represents a shift away from dichotomous Western thinking about regressions as negative and acquisitions as positive, away from a teleological drive towards a finished product that undervalues the process of development. Instead, this view embraces development as a process, and celebrates the fits and starts, the lurches ahead and the backward regressions. It embraces what have been called -but are perhaps not necessarily- "negative" experiences in the service of development, as a necessary part of life. This is one of several ways in which this view of development may be harmonious with the DIR approach. It is also one of the features of Touchpoints that lends itself to efforts to understand parent-child development in different cultures. It

represents a shift from a focus on milestones - with their differing cultural values, towards an understanding of the movement along the way, the fits and starts, the circles and cycles, the connections and balances. (Though many developmental events are universal, their meaning is often culturally bound.)

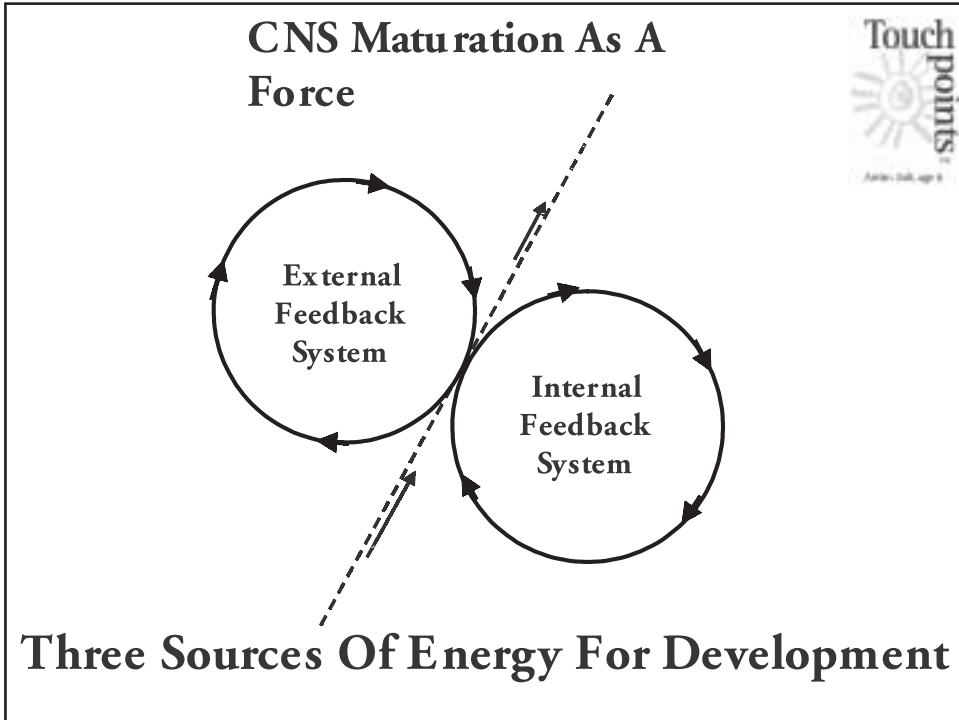


SLIDE: (FIGURE 1)

Figure 1 is a schematic representation of some of the forces driving development. Included in the internal feedback system “circle” might be included many of DIR’s ingredients for the emotional basis of development. The external feedback system refers to the caregiving environment - defined beyond a culturally narrow view to recognize the many cultures in which children are not raised within dyads, but instead, within communities; where not only mothers and fathers, but also other relatives and community members play essential roles. Brazelton underscores both the child’s sense of satisfaction and self-reinforcement when the child succeeds in doing something himself, and the importance of the response he receives from caregivers within the context of their relationships. Both approaches emphasize the pivotal role of the emotional life in pushing ahead other developmental lines. Systems theory begins to come into play here: these three forces—the child’s emotional life, the environment, and then the neuro-developmental biological force which relentlessly unfolds—together propel development.

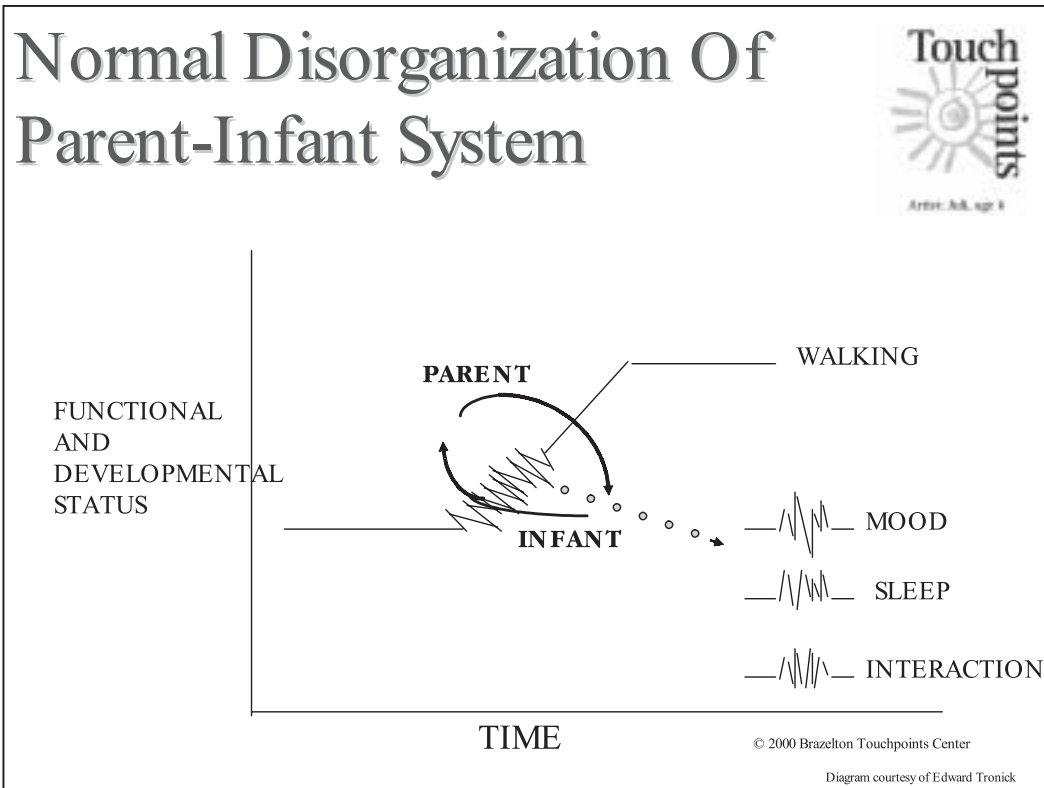
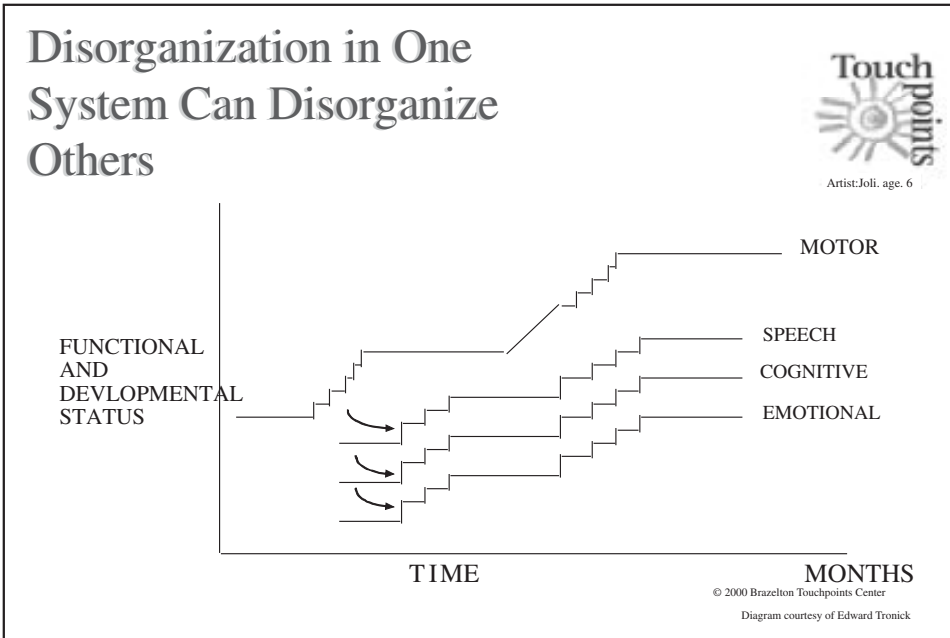
Another aspect of this “way of knowing” involves an economical, or energy model, which adds another dimension to this understanding of development as non-

linear and discontinuous. As development proceeds, the leaps and lurches are likely to be undertaken at some cost to the organism, often in the form of a regression, a transient loss of certain capacities, or a return to former behaviors—in the same developmental line, or a different one. These regressions may occur before or simultaneously with new acquisitions.



SLIDE (FIGURE 2)

As the child slides backwards momentarily, both child and parent become vulnerable. Professionals can view this vulnerability as an opportunity for anticipatory guidance. The goal is to deepen their relationship with the family, so that the family will be able to make the fullest possible use of this relationship. Professionals can help parents to see the child’s transient regression as a force that propels development, as necessary and predictable: understood in this way, such events are “touchpoints” of development. Sharing this view with parents can alleviate the anxiety such backsliding can induce, and may reduce the chances of fixating temporary regressions as more longstanding developmental deviations. Because this approach focuses on strengths, parents’ successes are reflected back to them by a professional who has shifted from a prescriptive to a collaborative role.



SLIDE: (FIGURES 3A AND B)

As with the DIR model, Touchpoints views the different lines of development as inextricably linked and interdependent. When there is a leap ahead in one area, the price may be paid in another. Figures 3a and b are schematic representations of this concept, though they do not fully capture the wide range of developmental lines potentially affected by this process. This is one of several areas in which the DIR approach might serve new efforts to adapt the Touchpoints “way of understanding” development to families with children with special needs, and in particular, with developmental disabilities.

If development is discontinuous, with steps backwards and forwards -which are often predictable-what does this look like in a child with special needs? What costs to the child, and family, might be predicted? As some occupational therapists have noted, children who are hypo-reactive and under-responsive, relying primarily on visual stimulation, are often likely to have very little motor output in the first 12 months of life. They often strike parents as being too easy. Then, at twelve months, when they stand up, suddenly the experience of gravitational force and of their feet in contact with the ground leads them to become extremely active with a sudden burst of abundant motor output. This may be a crisis for parents, who are bound to find their ideas about their child turned upside down.

The Touchpoints understanding of the course and multi-dimensionality of development might be used to chart a child with special needs’ development. Might there then be new information in the patterns of the curves (see Figures 1 and 3) that would facilitate early detection, and an understanding of a child’s needs over time? Are there similar or distinct patterns—from one disability to another, and as compared with “typically” developing children—whether the events are temporally similar or not? Are there other stops and starts, or other patterns to these events that wouldn’t be extrapolated from “typical” development, or from one disability to another? For example, perhaps in the first twelve months, a child with a particular developmental disability might not manifest the regressions that the Touchpoints model would predict. An “under-reactive” child, or an unlikely-to-protest-child who primarily shuts out stimulation, for example, might not manifest the regressions and backward slides. Might the absence of such regressions even serve as a warning flag for early identification? It might be highly productive if parents and clinicians could collect their observations of these patterns. We need a longitudinal picture of the process, not the product, not the developmental milestones, but the process of getting there. What would these lines look like in children with varying temperaments, with disabilities of different kinds, etc.?

Touchpoints posits development—with its regressions and new ground gained—as a neuro-biological force, though the course of the various developmental lines will differ to some extent from one child to the next. Though driven by biology, the course of development is potentially shaped, reinforced, and in some instances even directed by both the external caregiving environment and the child’s experience of his or her own development. A look at development in other species might shed further light on this view of development. What would these developmental patterns look like in non-human primates? Dr. Brazelton did in fact have the opportunity to

look at an early developmental touchpoint in primates when he examined an infant chimpanzee using his Neonatal Behavioral Assessment Scale. As he recounts, the baby chimp was almost as responsive as a human newborn to eye contact and cooing, following Brazelton's face with its eyes with intent interest. Just as Dr. Brazelton began to think "I'm falling in love with this baby chimp—she's just like a human," the newborn chimp suddenly grabbed his hair, hurled itself up to a chandelier and swung around the room.

### **Regression and Conflict in Developmental Processes: Evidence from Animal Models**

Unbeknownst to Brazelton when he was elaborating his Touchpoints model, a Dutch ethologist, Frans Plooij, was studying the developmental patterns of chimpanzees in the wild, and later compared them to human developmental patterns during the first twenty months of life. By quantifying contact-seeking and distancing behaviors in both chimp and human infants, Plooij found that there are similar discreet periods of regression, and conflict between parent and infant resulting from this regression, in preparation for a developmental leap. He points to patterns of predictable transitional periods of regression and conflict that alternate with stable periods, and postulates that the tension between them propels development.

In the unstable transitional periods, in both chimps and infants, there are regressions, just as Brazelton discovered in the "clinical nuggets" his patients presented to him. Progress in developing areas appears to decelerate, and the baby (chimp or human) becomes more demanding, reverting to earlier behaviors, clinging, crying, seeking out more contact with the mother. Plooij notes feeding and sleeping disturbances during these regressive phases, reminiscent of the regressions associated with Touchpoints. He also notes, in both chimps and humans, what he calls depressive behaviors, sitting or lying immobile, empty stares, rocking, and then a reversion to younger behaviors.

The mother's initial response is to wonder: "What's wrong?" In the human population, this often leads to what is sometimes referred to as "unnecessary episodic care": a mother will bring her infant to the pediatrician, who may blame the changed behavior on teething or a reaction to milk. At these predictable unstable transitional periods, though, the behavioral change often has a different explanation. Once the mother has been reassured that there is nothing physically wrong, she can allow herself a different response to the infant.

The mother then realizes that it actually would serve the child's needs for her to display her irritation with the regressive demands. It is her irritation, although she often at first feels guilty about it, that helps propel the infant's development. This understanding of the developmental role of a frustrated, and then benignly frustrating parental response shares common ground with DIR's prescription to parents for playful obstruction. A parent understands the challenge a child is facing, but also understands its necessity, and does not entirely protect the child from it. The parent

may dilute the challenge, or break it down into steps, allowing the child to face the challenge—a form of respect, perhaps, which helps the child to let go of regressive behaviors.

Plooij observes that in chimpanzees there is no increase in clinging and contact-seeking behaviors before nine months. Up until this time, the infant chimp is always carried—with an iron grip on its mother's chest hair. There is no opportunity for increased clinging prior to nine months, because there are no separations until then. This does raise questions as to the cultural basis of patterns of regression, conflict, and stable phases: in cultures that have different practices for infant-mother contact in the first nine months, one might expect these patterns to be different.

The human mothers Plooij studied said that they were comfortable with their babies' regression when alone with their infants and were ready to give in to the clinging and demands for more attention. It was the feedback they received from their husbands (wanting attention for themselves), or from in-laws and friends that made them uncomfortable with their babies. Plooij observed a difference in human and chimp mothers' shifts from the initial fretting and coddling response to their infants' regression to the eventual irritated urgings to move along. The chimpanzee mothers would let the infants remain in the regressed phases all the way through their apparently self-limited conclusions. But the human mothers intervened sooner in the regression to start shoving their children ahead. The chimpanzee mothers, as if to protect themselves from the pressures of mates and relatives, would take their babies and leave the pack at the beginning of a regression, or even before it came, as if they knew when it was going to happen, even before the researchers could tell. If the chimp mothers failed to remove their infants in time, the male chimps' neck hairs would bristle. The chimp mothers would then have to resort to various submissive behaviors in order to appease the males before they could escape with their demanding infants. It appears that the balance of indulgent and frustrating parental responses to infant regression varies across primate species and cultures, and that to some extent these are influenced by the social setting that parents are immediately affected by, and for which they are ultimately preparing their children.

In considering parental responses, though, it is critical to keep in view the child's contribution to parental behavior. Here it is the child's regression—predictable, perhaps at least partially biologically programmed regression in the service of development—that stimulates the mother's complex sequence of responses that then, in turn, fosters the child's further growth. Plooij and others speculate that the infant's regression may be set off by some early apprehension of a neuro-developmentally driven potential for change. This may be a new potential for learning, for a new kind of perception, for a new kind of understanding, for a new kind of processing that is present and in some way making itself known to the baby. The baby is frightened by it, holds on to the familiar, which is the mother's body, and returns to old familiar behaviors. But a little later, the infant will need the mother to push the baby to let go of the old ways, to grab on to new potentials, new ways of doing things—which are frightening. There is stress and cost in development. This kind of model of change underscores the relevance of the systems theory to development: the driving force

for change is a system involving family, and even—as is recognized more readily in “non-dominant” cultures—the larger social group. This model of change also suggests processes within the child and parents, between child and parents, and between parents and the larger social group that might be scrutinized in families with children with special needs. Perhaps there are opportunities for early identification, and intervention here—if only we knew in what way these patterns could be expected to be similar, or different.

Plooij has found that after an infant has gone through this process with the mother, the mother will notice that the infant is using new competencies. In this new stable phase, the baby will be less focused on the mother, more attracted to exploring his or her environment, more independent, and will play longer alone. The times at which these events occurred in human and chimp infants, were of course not identical, but seem to follow predictable, parallel patterns, and are similar to the timing of Brazelton’s touchpoints. One of the shortcomings with such models is that they inadvertently seem to reassert the hegemony of the chronological approach to developmental milestones. Yet they may assist parents and professionals in detaching themselves from chronology by pointing to qualitative features and patterns in the process of development which may ultimately reveal themselves to be more relevant to so-called “atypical” development. One of the important revelations of the DIR model is that it sets forth a process: wherever a child is in the process is to be valued, and is not measured chronologically. The parent’s contributions to this process are perhaps worth re-examining, however, in light of Plooij’s work, concepts such as DIR’s “playful obstructiveness”, and the systems theory approach embedded in Touchpoints.

### **Professional Participation in Developmental Process**

Touchpoints, though, looks within developmental processes for a set of “clinical attitudes” that can be referred to when at a therapeutic impasse, to allow for a kind of “righting” that professionals are bound to need from time to time as they react—humanly- to overwhelming circumstances. One of these attitudes is the acceptance of parenting as a process of trial and error, and, with this, parents’ expertise about their children. All too often professionals struggle to “break bad news” to parents without realizing that parents already know. Another is the power of using the behavior of the child as a “language” for professionals to use as they construct their relationship with parents; instead of telling parents what to think and do, the professional can share observations of the child with parents. Recognizing what we bring to the interaction is another “clinical attitude”: it is emotionally costly—as well as rewarding—for professionals to care for families of children with special needs. If the cost of this work to professionals is not faced, then they are unlikely to be able to bring the full extent of their strengths to bear on their work with families in these necessarily longterm relationships. Another attitude entails going beyond one’s traditional professional role, though certainly boundary violations are not advocated. If a

professional does cross a “boundary” in the service of a family with a child of special needs, she should be making herself less powerful as a professional and the families she works with more powerful.

One final “way of understanding” is the effort to look for the value in disorganization, for the opportunity in vulnerability. It is central to this approach to move beyond dichotomous categories of negative and positive, and to accept regression as necessary, as serving a purpose. This “way of understanding” entails a paradigm shift: development is understood and appreciated as nonlinear and multidimensional. Healthcare professionals make this appreciation available to the families they serve, focusing on strengths rather than negatives, healthcare professionals abandon prescriptive practices in favor of a collaborative approach, and shift from “objective” involvement to empathic involvement, empowering parents—and their children.

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# Chronic Pain and Pervasive Developmental Disorders

**Brenda Bursch, Ph.D., Lonnie Zeltzer, M.D.**

**Abstract:** *Sensory abnormalities have been observed in individuals with pervasive developmental disorders such as Autistic Disorder or Asperger's Disorder. Chronic pain can be the presenting symptom for those with a previously undiagnosed pervasive developmental disorder (PDD). Current understanding of pain transmission and inhibition systems suggests that these children are at risk for the development of chronic pain. They are also sometimes at a disadvantage in their ability to communicate their pain and distress. However, evaluation and treatment are possible and can be highly effective. Four cases are presented of children and adolescents with chronic pain who were unsuccessfully treated for their pain until they were diagnosed with a pervasive developmental disorder and treated with this diagnosis in mind. General treatment recommendations are also reviewed.*

Pain is the result of a dynamic integration of biological processes, psycho-developmental factors, and social context (American Pain Society, 2001). Nociception is the transmission of noxious sensory information along an ascending system of afferent sensory neural fibers from the viscera and somatic parts of the body (e.g. skin, soft tissues, etc.), connecting to interneurons in the dorsal horn of the spinal cord, and continuing up into the brain. These signals then go to different parts of the brain where they are influenced by a host of factors, including emotions, arousal and cognitions. The autonomic nervous system also plays a significant role both in the periphery as well as in the central nervous system. Ultimately these signals reach specific areas of the cortex (e.g. somatosensory I and II, lingula, anterior cingulate) where pain perception takes place. It is now believed that the affective component of pain is perceived in the anterior cingulate, while the sensory part of pain (e.g. intensity, duration, location) is perceived in the other pain perception areas of the cortex. However, the pain experience is also impacted by a pain inhibitory system comprised of a descending neural network from the cortex downward to the viscera and somatic parts of the body. Ascending and descending processes can be impacted by many factors, including: gender, age (developmental level), attention, arousal, memory, cognitive level, family learning, past pain experiences, culture, emotions, expectations, parental response, perception of control, relevance, and coping style.

Ultimately, the pain experience is a balance between pain transmission and pain inhibition with the end organ of pain perception being the brain (Zeltzer, Bursch & Walco, 1997).

Pervasive developmental disorders, such as Autism, are complex developmental disabilities that appear to be linked to biological or neurological differences in the brain. Individuals with PDD often have difficulties in verbal and/or non-verbal communication and social interactions. They may experience sensory abnormalities related to sight, hearing, touch, smell, and taste. Some may also have other brain disorders, including: epilepsy, mental retardation, Down Syndrome, and/or various other genetic disorders. The abilities of individuals with PDD spectrum disorders may fluctuate due to difficulties in concentration, cognitive processing, or anxiety. Touch or even just the proximity of others may be physically painful. Anxiety, fear and confusion sometimes result from being unable to understand or impact the environment in an intuitive way. Put simply, PDD can make it more difficult to predict and control one's body and mind.

To self-manage pain at a central nervous system level, an individual needs to regulate attentional focus, use flexible cognitive strategies to alter interpretations of and to cope with the pain, and be able to reduce arousal in order to reduce pain signaling (Bursch, Walco & Zeltzer, 1998). For children with PDD spectrum disorders, these are often particularly difficult tasks. Often parents must help regulate their young children until they can develop increasing skills to better regulate themselves.

A related problem is the difficulty associated with the measurement and characterization of pain in those with PDD. The identification and expression of various physical and emotional sensations is an extremely complex cognitive process and can be difficult to interpret (Finley & McGrath, 1998; McGrath, Rosmus, Camfield, Campbell & Hennigar, 1998). Normal toddlers do not separate emotional from physical distress. For example, a stomachache may reflect hunger, fatigue, or a need to use the bathroom. Young children (less than 5 or 6 years of age) often do not have the words to describe their sensations accurately. Even some older children, adolescents and adults, who are able to report specific somatic complaints, have difficulty identifying and/or expressing a description of their emotional experiences. This complex process is even more complicated for individuals with PDD spectrum disorders, who often have atypical experiences of sensory stimuli and who may have difficulty in communication.

Many chronic pain disorders, such as functional abdominal pain or even migraine and other types of headaches, are comprised of symptoms caused by a problem with the way the nervous system is working rather than by tissue injury, inflammation, or obstruction. That is, the etiology of many chronic pain conditions is an abnormality in neural signaling rather than a specific disease-related pathology. Additionally, pain that is initiated by disease can be exacerbated or maintained by disordered neural signaling. Due to the abnormalities in sensory processing experienced by some individuals with PDD, one would expect that chronic pain conditions would be a more common finding in PDD individuals. Surprisingly, little is written in the literature on this topic. The prevailing view in the scientific and professional

literature is that individuals with PDD are relatively insensitive to pain (American Psychiatric Association, 2000). However, in a recent study of children undergoing venipuncture, children with autism showed a larger behavioral pain response and appeared to be more pain sensitive than a group of age-matched children without autism (Nadar, Oberlander, Chambers & Craig, 2002).

Following, are four case presentations of pediatric patients, ages 3 to 20 years, evaluated and treated by our pediatric chronic pain program. Our initial evaluations revealed that each of these patients had features of a PDD spectrum disorder. Interestingly, none of the following children or adolescents was previously evaluated for or diagnosed with a pervasive developmental disorder.

### ***Case 1: Jack***

Jack is a 20-year-old college student who reported a three-year history of severe headaches. Jack saw multiple neurologists, was placed on a variety of medications that did not help, was unsuccessfully treated for “massive anxiety attacks,” was hospitalized for 5 weeks at a Headache Center with no improvement, and finally became hopeless and attempted suicide. Jack described three types of headaches. His daily baseline pressure headaches, infrequent “migraines,” and his “mental nausea.” This is the headache that he could not tolerate because it rendered him completely non-functional. These headaches were triggered every 1–3 days with too much sensory stimulation, such as when driving or watching movies. He wanted to be a mathematician, but halted these plans. He planned to kill himself if the planned UCLA treatment did not work. Jack had read the DSM and thought he met criteria for obsessive-compulsive personality disorder. Although not previously recognized, his history and mental status exam actually suggested features of a pervasive developmental disorder. He reported perfectionism, impaired concentration due to obsessive problem-solving (on topics such as the design of headlights), trouble reading social situations and engaging in effective social problem-solving, panic attacks in classes such as art, alexithymia, and dissatisfaction with his life, his school ability, his athletic ability, and his friendships. He said others described him as arrogant, but he was not sure why. He had always been notably clumsy and he has always had very few friends. Cognitive testing revealed an uneven IQ with a statistically significant discrepancy in his verbal and performance scores (Verbal > Performance). He did not acquire speech until he was 4 years of age, when he was also discovered to have a 75% hearing loss. He described his father as somewhat distant and as someone who has difficulty relating to people. He described his mother as someone who does not have good social skills and who has a significant amount of anxiety. Treatment: An eight-week inpatient pain rehabilitation program that included psychoeducation, physical therapy, biofeedback, acupuncture, family therapy, intensive cognitive behavioral therapy, and medication (Effexor XR 150mg bid and Klonopin 0.25mg qhs). Follow-up: Jack’s anxiety and depression were much improved at discharge. His pain continued to improve after discharge and is almost completely absent now that he has returned to college. He points to the following as being most helpful: (1)

he has a treatment plan that he trusts, (2) he has a conceptual model to understand his headaches and how to manage them, and (3) he has dramatically enhanced coping skills to address his somatic symptoms and anxiety that can exacerbate his pain.

### ***Case 2: Rick***

Rick is a 16-year-old male who had debilitating “migraines” for six years. His headaches were located in the “core” of his brain, and triggered mostly by activity or the smell of coffee. He had been hospitalized many times for pain and nausea. CAT scan, MRI and lumbar puncture were normal. He had been treated with acupuncture, homeopathy and biofeedback, and tried on over 30 medications. He stated that the only things that were abortive for his headaches were opioids. Triptans and DHE both made his headaches significantly worse. Again, although not previously evaluated or recognized, his history suggested features of PDD. For example, when younger, he did not smile or show interest in his mother; he did not respond to comforting by his mother; he had to be taught to respond to greetings of others and reminded to reciprocate; he had to be taught and reminded to respond to his cat’s cries when he was being too rough with him; and he verbalized that he had difficulty with empathy and reciprocation, and described it as more of an intellectually-based rather than emotionally-based behavior. He did not distinguish modes of affection with people in different roles (mom, doctor, friend) and was unusually affectionate with all. He told stories and lied without regard to the impact of these lies on others. When confronted, he appeared amused. Only when taken step by step through the consideration of the impact on others did he understand. He was honest about things that others would screen for purposes of social grace, and had preoccupations with oppression, somatic symptoms and pharmacology. His focus on somatic symptoms and medications was present by the time he was 9 years old. His rigid thinking was not influenced by experience. Due to anxiety, he was unable to go to school, go to malls, use public bathrooms, go into crowded areas, go to poverty-stricken locations, etc. He had fine motor impairment and very poor handwriting. He had notable sensitivity to certain noises, such as a heater going on or the wind when the car windows are rolled down. Cognitive testing revealed a statistically significantly uneven IQ (with Verbal scores > Performance scores). Treatment: An eight-week inpatient pain rehabilitation hospitalization that included an opioid wean, psycho-education, physical therapy, massage, family therapy, cognitive behavioral therapy, and medication (Zoloft 200mg; Risperidone 2.5mg; and Mellaril PRN 10mg). Follow-up: At the time of discharge, Rick’s anxiety was much improved. He was able to go to a mall and attend school. He remained perseverative about medications, making him high risk for substance abuse. After one year of day-treatment, he achieved his stated wish of attending a Boarding School. He is currently off medications, excelling academically, and just now achieving insight into his own psychological functioning.

***Case 3: Jim***

This is an eleven year old boy with two years of abdominal pain. He was evaluated by a urologist and two gastroenterologists. A voiding cystourethrogram, an upper GI series with small bowel follow-through, a KUB and abdominal ultrasound, and a CBC with differential and chemistry panel, urinalysis, and stool tests were also all normal. He also saw a neurologist at age 6 for presumed ADHD. EEG was normal. Jim was tried on short trials of Dexedrine, Wellbutrin, Prozac, Tofranil, Tegretol, imipramine, and disiprimine. None of the medications were helpful. He frequently had motion sickness. Although not previously evaluated, his history and mental status exam also suggested features of PDD. For example, Jim did not speak until he was age three and did not point to things to communicate. His parents do not know if he understood what they were saying to him. When he got frustrated, he hit his head, punched walls or threw things. He had always been hypersensitive to certain sounds. He tended to play by himself and had no friends. He used to play with a wheel, turning it over and over, and did not like to play with toys in general. Now, he will play with a pen in a similar manner. He has generally been clumsy, and reports that he cannot ride a bike without training wheels. He was blunted and irritated during the interview, not socially reciprocal or nonverbally communicative. His voice was monotonous with an unusual use of words at times. He was concrete, serious and echolalic. He endorsed rituals in the bathroom related to being well organized and dry. He endorsed sometimes having too many thoughts in his head at one time. He spontaneously reported that he panics about once per week about tests, reports, school, being punished, or to scary sounds in the house. He said he worries about “everything that comes to my mind.” He endorsed significant alexithymia and social discomfort. When asked if he was worried when his grandmother had a stroke in front of him, he said, “I just never experienced the incident before.” Outpatient treatment: Psychoeducation and referral for further evaluation of PDD, Prozac 10 mg qd; massage therapy; and amitriptyline. Follow-up: The medications controlled his symptoms and he was extremely responsive to massage, moaning with pleasure. He was diagnosed by the Autism Evaluation Clinic with Autistic Disorder and provided with specific recommendations and referral to Regional Center for special services.

***Case 4: Carl***

This is a three year old young boy with chronic severe headaches for one year. Imaging studies and neurology evaluations were negative. Depakote, Claritin, and Propranolol were tried and discontinued since headaches continued. Headaches were described as generalized after prolonged exposure to multiple stimuli, such as loud noises (e.g. when fire trucks passed the house) or playing with multiple children. He would typically lie on the floor, scream, and hold his head. He also had a history that suggested features of PDD. His gross motor skills were delayed, however he was performing his ABC's in two languages and speaking in four word sentences by 19 months. He demonstrated no separation anxiety when he left his mother for school

each day, but always needed to know her location. He monitored if people were following rules or not, and had considerable difficulty with other transitions. He had extreme hypersensitivity to sounds and clothing textures, and would only wear soft cotton. He tended to play by himself. When he did play with other children, he was often picked on. He played better with well-behaved, older children as he knew those social rules. He was unsure what to do with children who were misbehaving. He was highly organized, and asked his father each day if he had remembered his belongings (cell phone, briefcase, etc) before he left for work. He had frequent tantrums. Outpatient treatment: Psychoeducation with parents; Prozac 1.5mg PO daily; decrease environmental stimuli during a headache or if there are loud noises (for example, plugging his ears at the sound of an emergency vehicle siren); and age-appropriate social skills training. Follow-up: Headaches resolved on Prozac and environmental interventions.

## **Discussion**

Treatment recommendations and referrals should target both the suspected pervasive developmental disorder and the pain disorder (as well as other physical symptoms). Because of the overlapping neurobiology of these disorders, a number of interventions will address both issues. These will be discussed below.

Interventions should address possible underlying sensory signaling mechanisms, specific symptoms, and disability. In general, treatment goals focus on increasing independent functioning (activities of daily living, academic, social, physical); remediation of specific symptoms, deficits or problems revealed in the assessment; enhancing communication in ways available to the child/adolescent, especially of non-symptom related distress, with peers and family members; and facilitating more adaptive problem solving skills. Some children with PDD may be best served by a structured education and behavior program that contains a one-on-one teacher to student ratio or small group environment. However, many other children are quite successful in a fully inclusive general education environment.

Treatment techniques designed to address possible underlying sensory signaling mechanisms and specific symptoms might include structured cognitive-behavioral strategies (e.g. psychotherapy, hypnosis, biofeedback, or meditation), behavioral techniques, family interventions, physical interventions (e.g. massage, yoga, acupuncture, TENS, physical therapy, heat/cold therapies, occupational therapy), sleep hygiene, and pharmacological interventions. In general, interventions that promote active coping are preferred over those that require passive dependence.

Family interventions can be extensive and critical to improvement. Such interventions include helping family members to understand the nature of diagnoses (including relevant medical, cognitive, behavioral and/or psychological contributions), facilitating acceptance of a treatment approach, elucidating biopsychosocial factors that likely contribute to the somatic symptoms, altering family patterns that may inadvertently maintain or exacerbate the symptoms, helping parents to cope

with their own and the child's distress during the assessment and treatment process, and developing a long-term plan, with referrals to appropriate resources, to ensure adequate support for self-management of symptoms and to optimize independent functioning.

Pharmacological interventions are geared towards quieting the CNS arousal and enhancing the regulatory mechanisms of the brain. The specific medication choice depends on the likely neurophysiologic and neurochemical contributors to the symptom. Classes of medications to consider include: tricyclic antidepressants (TCA's), selective serotonin reuptake inhibitors (SSRI's), anticonvulsants (e.g. gabapentin), muscle relaxants (e.g. baclophen), and low dose phenothiazines (e.g. thioridizine). Low dose TCA's, such as amitriptyline, given at bedtime, can help with neuropathic and irritable bowel syndrome pain, and have the added advantage of facilitating sleep. SSRI's can reduce the anxiety components underlying many pain symptoms in children and facilitate sleep if anxiety is a component in sleep difficulty. Phenothiazines have relatively rapid onset and can play a significant role when anxiety is a major contributor to the symptoms and when the SSRI has had insufficient time to be effective.

## **Conclusion**

Sensory abnormalities have been observed in many PDD spectrum individuals. Chronic pain, or other somatic symptoms, can be the focal symptom for children and adolescents with a previously undiagnosed pervasive developmental disorder. Evaluating and treating chronic pain in the child or adolescent with a PDD spectrum disorder can be difficult but is not impossible. These children appear to be at risk for the development of chronic pain and are often at a disadvantage in their ability to communicate their pain and distress, at least specifically enough for early identification and treatment. However, evaluation and treatment are possible and can be highly effective. While there are many interventions that have been demonstrated to be helpful to improve overall functioning in children with PDD, research is needed to validate initial observations of seemingly effective treatments for chronic somatic symptoms in this population. Additionally, more research is needed to understand the variety of experiences of pain in children and adolescents with PDD spectrum disorders.

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# Case Studies of Graduate Students Implementing DIR Programs

**Travis Bradberry, M.S. and Josh Feder, M.D.**

**Abstract:** *The Developmental, Individual Differences, Relationship-Based (DIR) intervention approach incorporates multi-modal treatment for developmentally disabled individuals. The use of a graduate student acting as a 'big brother' to conduct floor time with moderate to high functioning children and adolescents with autism spectrum disorders is described. Two cases are presented in detail in which this intervention moved two adolescents on the autism spectrum forward in their ability to relate, socialize, use language, and regulate emotion. This intervention was conducted as part of a treatment "team", which also included educational and biomedical interventions.*

## **Introduction**

Dr. Stanley Greenspan, Dr. Serena Wieder, and colleagues have developed and written extensively about an approach for treating developmentally disabled individuals (Greenspan & Wieder, 1998, 2000a). This Developmental, Individual Differences, Relationship-Based (DIR) approach targets the multifaceted needs of individuals with autism spectrum disorders and regulatory disorders. These individuals differ in the developmental level of their communicative, cognitive, and emotional capacities (Greenspan, 1992). These capacities include the ability to regulate affect, engage with and relate to others, use ideas in a meaningful way, and problem solve in social situations. Individual differences in sensory modulation, auditory and visual-spatial processing, and motor planning and sequencing comprise another functional area. The final functional area of the DIR approach includes an individual's learning style and the patterns of their relationship with their peers and primary caregivers (Greenspan & Wieder, 2000b). All of these functional areas influence the developmental profile of the individual, and should be considered in creating a multi-modal treatment program. In this paper we describe a use of the DIR approach with two individuals with autism spectrum disorders who were thought to have slowed significantly, or stopped, in their development.

## **Fundamentals of the DIR Intervention**

The foundation of the DIR intervention is to foster protective, stable, and secure relationships within the family. The importance of this first step should not be overlooked in providing the client with the support and stability needed to move forward. Counseling to help the family cope with caring for an individual with special needs is essential, especially for those families who already meet the basic needs of physical and emotional contact, medical care, housing, and nourishment. Another integral aspect of the DIR approach, which serves as a foundation for later, specific interventions, is the formation of relationships with significant others which are nurturing, trusting, and ongoing. These relationships, which should be present with all caregivers that come into contact with the client, are essential to the development of warmth, intimacy, and pleasure. These relationships also provide the client with a format for learning adaptive behaviors, communication, and symbolic representation (Greenspan & Wieder, 2000). All family and caregiver interactions should be developmentally appropriate for the individual. Interactions are then geared towards moving the individual out of maladaptive modes of functioning towards more effective and developmentally appropriate behaviors through pleasurable activity (Greenspan & Wieder, 2000).

Caregivers can engage the child in an atmosphere that is familiar to him or her. In this setting, they can participate in imaginative, playful activities that are pleasurable, soothing, and provide learning. Moreover, they engage in these activities in lieu of activities which are self-absorbed or perseverative (Greenspan, 1992). This affords the family and caregivers the opportunity to conduct intensive intervention with their child. This intervention is aimed at improving an individual's spontaneous, developmentally appropriate interactions; semistructured problem-solving interactions; and motor, sensory, and visual-spatial activities. The intervention accomplishes these tasks through the caregiver engaging the child on their "turf".

Indeed, although it is frequently associated with treating children, DIR interventions can be initiated at any age and in a variety of circumstances. Individuals are capable of making significant developmental progress throughout adolescence and adulthood. Appropriate and effective interventions can be initiated at any age. Too often, caregivers with adolescents and adults assume they have reached a point where they can no longer make major gains and teach superficial skills and routines, instead of attempting to foster development (Greenspan & Mann, 2000).

Greenspan and Wieder (2000) recognize the need for DIR intervention with patients of all ages. When referring to floor time in general, they recommend that "other family members and people (e.g. graduate students and volunteers) should be trained in the methods and principles of floor time and be scheduled in to help implement the program." Indeed, even tutors with limited expertise are often useful in implementing programs that target learning disabilities, literacy, and emotional disturbances (Blake, 2000; Fitzgerald, 2001; Vadasy, 2000).

Bringing in outside resources to conduct a home-based intervention is often helpful and at times necessary for its success due to the limits of any family in time,

energy, and wherewithal to conduct intensive DIR intervention. In addition, trainers may diffuse the negative emotional responses (such as when a child is unresponsive, perseverative, or overly active) children sometimes have when working with their parents. In the interest of relating to children and adolescents in particular, a trainer can be brought in to act as a “big-brother” (or “sister”) when implementing a floor time intervention. This approach must be conducted carefully, taking into consideration the possibility that the family may have trouble owning the intervention or in relying too much on a trainer to develop these relationships. To our knowledge no one has ever written about clinical case studies utilizing outside tutors to act as “big-brothers” while conducting a DIR approach.

## **Method**

Several college students, including a graduate student in psychology, assist with DIR interventions in the San Diego area as part of a multi-modal treatment approach for children and adolescents. The majority of the patients are developmentally delayed and/or on the autistic spectrum although the intervention has also been helpful for other conditions such as ADHD, anxiety, cerebral palsy, and bipolar disorder. To date, nine different individuals have received DIR intervention from one particular graduate student. All work is supervised by a psychiatrist familiar with DIR and floor time. Each case begins with initial training sessions in which the interventionist meets with the psychiatrist and learns about the child’s personality, family situation, and DIR profile. With the first few clients, initial sessions were accompanied by training which included observing the psychiatrist engage in floor time with the child and extensive reading into the DIR method. The interventionist learns under close supervision by the psychiatrist, that is, if he meets with a client several times during the week, he meets with the psychiatrist weekly to review what they are doing, what works, and what they might try next. As the graduate student gains more experience, new cases are reviewed in regular supervision without the clients present. The families continue to work with the psychiatrist, and the intervention is framed as an extension and elaboration of the clinical psychiatric intervention.

The graduate student sees the client at home, school, beaches, restaurants, and other locations that promote near age-appropriate activities and interactions. Sessions vary in length, but are usually two hours in duration. Sessions with younger children, ages 8 through 11, are rarely over three hours in length. Sessions with older children, particularly those in high school, tend to be longer and occasionally last five or six hours. Most clients are seen once per week during the school year and twice per week during school holidays. Families with additional need and resources hire the interventionist to work with their child up to forty hours per week. While this is not the norm, several families have their child seen 10–15 hours per week, particularly during school holidays. The duration of the intervention varies on a case-by-case basis. Some individuals are seen several times per week for an intense treatment

program ranging from two weeks to two months. Others are seen on an ongoing basis ranging from months to years.

All work conducted by the graduate student is closely supervised by the psychiatrist. The graduate student documents each session with progress notes describing the day's activities, the child's behavior, and the interventions conducted. Progress notes for each client are presented to the psychiatrist in regular meetings, from one to three times per month depending upon the intensity of the work. Additional supervision is also provided by phone as situations occasionally arise that require more immediate assistance. Over the course of this work, supervisory discussions focus first on one client, then two. As the graduate student gains experience, more clients are served, and discussion of ongoing work with individual clients is more concise. Supervisory discussions range from a few minutes to one hour per child, depending upon the amount of time spent in intervention during the previous weeks and the current status of the case. Additional readings are frequently discussed relating to child development or new developments in the field, especially information that is pertinent to the condition of the individual client.

Intervention sessions are closely tailored to the unique developmental profile of the individual. Activities are structured to foster many areas of concern including social skills, relatedness, reciprocal interaction, emotional regulation, sensory integration, motor planning, and developmental progress. Sessions frequently consist of age-appropriate social activities, and peers are often brought in to join the session. The majority of the intervention is conducted outdoors, using common games such as catch, basketball, football, bowling, and golf as vehicles for pursuing relationship-based learning and relating. Emphasis is placed on skills and schoolyard games that can be used with typical peers. In addition, school aids are coached and trained to facilitate these interactions. Higher functioning individuals have increased their repertoire of activities to include bicycle motor cross (BMX), wall climbing, and surfing. The strength of the intervention lies in its flexibility. Activities can be altered day-to-day and even during sessions. The interaction is dynamic and incorporates all tools available in society at large. Books, computer software, audio-visual equipment, and even going to a fast food restaurant to practice taking an order and talking to girls have all been included when they meet the developmental needs of the individual being treated.

Movement is the primary mode of treatment because this form of interaction is essential for the development of normal peer relationships. A great deal of male adolescent interactions happen in physically active settings. Most treatment providers for these individuals are unable, due to physical and space constraints, to provide a physically active intervention. The use of a graduate student interventionist who is young, physically active, and trained affords the opportunity for physically active DIR intervention as one component of a multi-modal treatment team. Many of the activities are semi-structured. For example, a favorite activity such as basketball is used. In the context of a simple game (for example, "1 on 1"), the graduate student coaches, woos, and cajoles the boy into appropriate interactions for the game. Another example: in restaurants the graduate student coaches appropriate ordering while giving choices

to the adolescent. As a result, social skills training is imbedded into the activity in a fluid and dynamic way.

## Vignettes

### Troy: An Autistic Adolescent

Troy began his sessions with the graduate student at the age of fourteen. Before this point, he received two hours per week of speech therapy since the age of four, special education services through his school, and seven months of office-based DIR intervention with the psychiatrist. Upon beginning treatment, Troy had an intense sensitivity to sound and would wear earplugs on a daily basis. His gross motor coordination was quite good, as could be expected from an individual whose father is an accomplished athlete. Troy was a competent swimmer and dabbled in kayaking, boogie boarding, and surfing. Troy had extreme tactile sensitivity and a very restricted diet consisting of white, bland food. He vomited if forced to touch certain foods to his mouth, including many types of fruit. In addition, he had poor sensory modulation and would frequently engage in various forms of self-stimulating behavior. For example, he frequently pressed his forearms against objects such as walls and shelves and he squeezed his pectoral muscle between his hands.

At this time, his functional developmental capacities were poor. He spent the majority of his time in his room with the door closed watching television, looking at comic books, and playing video games. He engaged very little with others. He generally only spoke to his father and mother and rarely responded to others who attempted to engage him. Indeed, his speech was severely limited. It consisted of one to two word utterances which were mainly immediate echolalia. However, he was quite capable of initiating purposeful gestures. For example, he accurately said “turn right” while giving directions in the car. Complex problem solving interactions, i.e. the ability to logically sequence ideas for communication, was absent. An interchange might sound like;

*Interventionist*—“Hey Troy, I got us a tee time, want to go play golf?”

*Troy*—“Go to McDonald’s.”

*Interventionist*—“So, you don’t want to play golf.”

*Troy*—“Go to McDonald’s.”

*Interventionist*—“Why don’t you want to play golf?”

*Troy*—“Ya.” (which might mean yes or leave me alone)

*Interventionist*—“Would you rather eat than exercise?”

*Troy*—“Get a Chicken McNuggets.”

*Interventionist*—“So are you saying that you are hungry?”

*Troy*—“Troooooooooooy huuungry.” (odd, prosody, sing-song voice)

*Interventionist*—“Can we go play golf play golf after we eat.”

*Troy*—“Ya.”

*Interventionist*—“Do you really want to play golf?”

*Troy*—Nods head

*Interventionist*—“Does that mean yes?”

*Troy*—“Yeessssss!” (and nods head which for Troy truly meant yes).

Troy had little ability to answer “what”, “why”, or “where” questions and had no appreciable understanding of social nuances.

His parent’s relationship ended in divorce shortly after he began treatment. He saw his father approximately one afternoon per week. They typically swam laps together or attended karate classes. His father was a stern disciplinarian who occasionally took him places where he provided little or no supervision. When he interacted with his mother she was warm and affectionate, but had difficulty increasing his quantity and quality of speech.

Troy’s treatment program began with an extensive assessment phase followed by two hours of floor time each week with a psychiatrist. The psychiatrist helped to facilitate his school’s development of an individualized educational program, and his mother (and occasionally his father) was present at therapy sessions. A few months after treatment began, his parents and his psychiatrist solicited the help of a college student who was about to graduate from a local university. This individual received training in the fundamentals of the DIR approach and began working with Troy five hours a week. Later in the intervention, the graduate student increased time spent with Troy to approximately 10 hours per week during school and 20 hours per week during summer breaks from school.

Initial sessions were split between the home and local parks. Troy was eager to spend time with his new “friend”, but getting him to engage in reciprocal activity was a struggle. Activities at the park, such as playing catch and skateboarding, quickly turned to Troy becoming silly and running off. He frequently disengaged, made loud noises, and attempted to abandon the graduate student. When he ran off it was not always clear whether he was testing to see if the graduate student would follow him or he was merely running off. Both seemed to occur.

At home he engaged with the graduate student in activities such as board games or the computer, but Troy instructed him to “leave” long before the session was finished. Troy seemed to want to end the interaction, preferring to be alone. However, the interventionist persisted. Meaningful interactions between Troy and his interventionist were limited. He usually spoke in one-word utterances, and as noted above a “yes” often meant ‘leave me alone’. He frequently engaged in self-stimulatory behaviors such as “flapping” with his fingers and applying pressure to different areas of his body. Troy also badgered the graduate student and psychiatrist by touching them on the leg, flapping his fingers in their face, and making noises in their ear. Troy’s self stimulatory behavior, including general silliness and screeching sounds, dominated the early sessions and impeded engagement between him and his caregivers. This behavior was addressed during the intervention by engaging him in more fruitful interactions when possible and at times by setting limits on the behaviors themselves.

Nearly six months after the graduate student interventionist began working with Troy, significant changes took place. He became more able to tolerate the presence of another person and this allowed for more social engagement. He approached the graduate student more and more. Troy's level of engagement increased to the point that new activities could be introduced. He and the interventionist began building and launching model rockets and Troy took intense pleasure in this activity. This activity also afforded them a myriad of emotional interactions, such as when a rocket that took several hours to build would get stuck in a tree. These interactions were fertile ground for improving Troy's speech and engagement and he responded with multi-word phrases such as, "Get the man with the tool to cut the trees down." This particular phrase was one of the longest he had ever been known to produce. Troy produced this truly incredible phrase, nearing a kind of theory of mind, in the context of a rare and intense affective attachment to the rocket. The rocket seemed to represent a transitional play object (it could be fired off and retrieved instead of Troy needing to run off). The loss of the rocket was therefore very upsetting to Troy. The associated affect, we think, was a driving force behind this amazing statement. The floor time conducted outside the psychiatrist's office had a tremendous benefit due to the intensity of the treatment and the complexity which real world activities afforded.

Troy's compulsive behavior continued, but was more often accompanied by language. For example, when he grabbed someone's leg he usually said "Don't touch (insert name here)'s leg." Troy's awareness of his behavior increased, and he began to connect it to the reactions of those around him. Consistent with this awareness, he controlled the behavior better, and this improved his engagement with others. That is, he used the phrase with the behavior, but did the behavior less often and ended it sooner. This left him calmer and more able to engage.

Six months into the intervention, Troy initiated a more complex interaction between Troy, his psychiatrist, and his interventionist. Troy had recently finished two weeks of Berard-style auditory integration training and he took an interest in music. The graduate student introduced him to new CD's that they listened to in the car. Troy brought these CD's to the psychiatrist, and used them to generate discussion. For example, he asked his interventionist to take him to the doctor's office to show the doctor a new CD. The discussion surrounding Troy's plans provided ample opportunity to generate speech and develop more subtle kinds of both affective experience and regulation.

Ten months into the intervention, Troy made additional gains in the area of spontaneous and descriptive speech and in his ability to answer open-ended questions. Affect-charged symbolic material helped Troy answer open-ended questions. For example, Troy loved to read comic books and he identified with a particular character. This character spent his days blasting "bad guys" with automatic weapons. While we eventually restricted these books due to their violent content, his interest improved his ability to talk about them. Troy answered questions such as, "Who got shot?" (the bad guys) and "Who shot them?" (the character). At this point in time, he

could not explain why the character shot anyone, but he enjoyed talking about the character's behavior and angry smirk.

At this time the graduate student introduced Troy to a board game called "Weapons and Warriors", in which each player shoots at the other's castle and men with marbles fired from miniature crossbows and catapults. As time went on, Troy thoroughly enjoyed the game. During each session, the graduate student highlighted affect-laden events, showing Troy the appropriate behavior and asking him to do the same. Gradually the game became highly affectively charged for Troy as he struggled to win. Upon reaching victory, he would throw his arms up in the air and yell, "I win!" This game was the start of Troy's blossoming competitive spirit, a product of being truly engaged in the activity at hand. During the game, the interventionist created, or helped Troy create, a "battle-cry" before each turn. Battle cries were aimed at scaring the "men" near the opponent's castle. Troy's battle cries became spontaneous and independent, and increased in complexity the more they played the game. They were most dramatic when his affective involvement in the game was greatest. During the same month in which major gains were made through the use of the comic book character, long battle cries such as, "I'm gonna shoot the guy at the rock and it's gonna fall," were initially surprising, but later not uncommon.

Twenty months into the intervention, Troy's ability to answer some "w" questions (who, what, when) had improved. He answered questions that, at times, enabled him to engage in everyday conversation. This improvement was partly attributed to the constant attempts of his interventionist to engage him in such dialogue. In the beginning, Troy was given options if he couldn't answer an open-ended question and gradually he was able to decipher the meaning of some of these questions. This was a slow process that required a great deal of persistence on the part of both parties and many unsuccessful attempts. At one point, after a trip to a football game, he explained where he went, who played in the game, who won, and who lost. After Thanksgiving, he shared that he went to his Grandmother's house. When asked what he ate, he listed several of his favorite items from the table. His ability to use descriptive speech to describe quantity and quality also greatly improved. At the zoo he was asked, "What's that?" when looking at an 8 foot boa constrictor. He replied, "Big snake." When asked, "What's this?" while looking at a 20-foot python, he spontaneously replied, "Giant snake!" Troy also developed an increasing tolerance for sound. At the request of his interventionist, he only wore his earplugs during times of extremely irritating sounds. These sounds included the click of the turn signal in a car, crying babies, and crowded restaurants. Without the earplugs, he was more able to attend to verbal cues from those around him.

At this point in time, Troy's ability to incorporate affect into strings of speech improved. His battle cries in Weapons and Warriors grew in their affective content, and he began to generate affect-laden, spontaneous verbalizations at other points in the game. When his the graduate student knocked down his men and cheered, Troy responded with comments such as, "Oh, you killed me! You just gonna die!" Affective expression was a welcome addition to Troy's life and it coincided with an increased awareness of the world around him. At this time, Troy frequently revealed

his savant behavior of remembering dates. The following interaction from October of 1998 typifies Troy's ability to recall dates as manifested by his newfound strength in answering "w" questions:

*Interventionist*—"Who broke Arnold's arm?" (Referring to a broken action figure)

*Troy*—"Troy did."

*Interventionist*—"When did you break Arnold's arm?"

*Troy*—"On Sunday November 23rd 1997."

*Interventionist*—"Where did you do that?"

*Troy*—"In Dr. Feder's office."

The interventionist verified this and several other dates that Troy provided for specific incidents and found that they were most often correct.

Troy's personal awareness and repertoire of behaviors increased to a new level. Troy's days of consistent self-stimulatory behavior and running away were long gone. He engaged in more complex reciprocal social activities with his interventionist. The interventionist worked towards taking strings of interactions, for instance in the course of a golf game, and moved Troy toward a more global appreciation of playing the game. Indeed, Troy began to request activities and was allowed to set the schedule for how he and his interventionist would spend their time. He chose to participate in dynamic sports introduced to him by the interventionist such as surfing and golf. Two years into the intervention Troy had the physical skill and emotional regulation needed to play 18 holes of golf on a championship-size course, paired with his interventionist and two strangers. He also chose where he and the interventionist would stop for a bite to eat, ordered for himself, and engaged in brief interchanges with the staff and clientele. This is not to say that Troy appeared normal, as his mannerisms, speech, and attire were odd. However, he had certainly come a long way from spending his days sitting in his room looking at comic books.

During this stage, 20–24 months into the intervention, new problematic behavior surfaced. Troy expressed an overzealous interest in sexuality, coupled with obsessive concern surrounding illness and death. Greenspan and Mann (2000) allude to this development in referring to children who begin to engage in triangular logical thinking:

Children who reach this level take a greatly expanded view of life and show an interest in all facets of their world. They become curious about their bodies, sex, anger, death, where their parents came from, and about anything else that even remotely touches their lives.

Greenspan and Mann's statement sheds light on Troy's situation. Not only did he develop these interests simultaneously; they arose when he developed triangular logical thinking. For example, he directed the interventionist to take him to his favorite burger joint clearly for the purpose of seeing particular girls who worked there. This was problematic because he would thrust his fists into his stomach and chest with an orgasmic appearing sigh and gyration directed toward his favorite blonde waitress. In addition, Troy developed a compulsive cough every time someone close to him

fell ill. Several trips to the doctor revealed no infection, just an irritated throat from his obsessive coughing. Troy's most severe bout of coughing came when his mother had intense back pain and he feared that she might die. Troy spent lengthy periods patting and soothing her, telling her that it would be okay. However, he expressed his fear to his psychiatrist and interventionist that, "(Mom's name) gonna die."

After a few months, Troy became irritated with anyone who coughed around him. Troy's anger manifested itself in fits of yelling and finger pointing at those who let out even the slightest cough. Interestingly enough, the majority of these fits of rage were directed at close family members and the girls he was attracted to at his favorite restaurants and stores. Troy's violent yelling was startling and frightening, and his sexual gyrations generated stares of disbelief. Greenspan and Mann (2000) query:

What about a child who is very, very concrete and just has the bare minimum of some verbal concepts, who can answer "why" questions but can not do gray area and triangular thinking? What happens when these changes in the body, sexual interests, and level of aggression happen in children whose processing and functional capacities are weaker?

The kind of child described in the above quote closely mirrors Troy although he was beginning to develop triangular thinking. His processing and functional deficits left him unable to appropriately manage his new developmental challenges such as sexual desire.

In fact, most developmental gains brought new challenges for Troy which were dissected and examined. Behavioral control for Troy came from extensive intervention and an exploration of the motivations for his behavior. Intervention during this time averaged twenty hours per week with thirty hours per week during summer break from school. Explorative, affect-laden discussions of books and computer software on the human body, illness, and sexuality helped Troy increase his understanding of these newfound topics. In addition, we encouraged his family to ground Troy when he acted out. Troy quickly learned that yelling at people was not appropriate and would keep him from his favorite activities. Troy had gone from a fourteen year old who said little, acted silly, and ran away from his interventionist to a sixteen year old who verbalized many of his ideas and controlled his intense desire to act out.

## **Troy in Perspective**

DIR intervention, conducted by the graduate student interventionist, was initially directed towards an adolescent who had a narrow repertoire of mostly sedentary interests and a limited capacity for speech and engagement with others. Forming a bond between the two of them was a slow process, and Troy frequently acted out, as he had great difficulty regulating his behavior. Over time, Troy tolerated the presence of the interventionist and learned to enjoy connecting. The quantity and quality of his speech improved as did his ability to engage with another in a purposeful inter-

action. The active, physical quality of the intervention we feel was critical to helping Troy self-regulate so that this progress could occur.

The result of this intervention was a blossoming for Troy and a life that was dynamic and filled with new activities and interests. Troy learned to enjoy several reciprocal, outdoor activities, and he identified greatly with his “ownership” of these activities. The richness and complexity of Troy’s relationships with family and other significant individuals in his life increased as his ability to truly engage and close circles improved. Troy continued to function well below his age level in almost every capacity, but his progress as a result of the intervention was observed and enjoyed by everyone involved, including Troy himself.

### **Craig: A High-Functioning Adolescent with Asperger’s Syndrome**

At age 15, Craig, a high school freshman, was an adolescent with Asperger’s syndrome who struggled to fit into the mainstream. As a child, he spent time in various public schools before his parents chose to place him in a private school for learning disabled children. The public schools had difficulty meeting his needs, and it was felt he would “fit in” better at the private school. Socially, he was withdrawn and had difficulty relating to others without being perceived as odd. His speech was loud and pedantic, and he walked with an awkward gait.

Craig took psychotropic medication since the seventh grade that is moderately helpful with attention and rigid thinking. He participated in a social skills therapy group during sixth through eighth grades. Craig received special education services at a school for learning-disabled children during the fifth through eighth grades.

At the time Craig began seeing the graduate student interventionist, in ninth grade, he was facing possible expulsion from his high school. He failed to remember classmate’s names and frequently walked into classes other than his own. These disruptions often occurred during the middle of lecture and he asked teachers questions in a loud, odd voice. His mediocre performance in the classroom also affected the school’s perception of him. Craig presented with a good vocabulary, but he was highly pedantic and limited by a severe stutter. The form of the stutter was that of a compulsive repetition of words or phrases that profoundly hindered speech, especially when he was anxious.

Craig’s motor coordination and planning were impaired although he did show excellent perceptual-motor functioning with well-practiced video games. Craig’s impairment in fine motor coordination affected his handwriting and limited his ability to participate in athletics. Craig displayed difficulties in auditory processing, including sensitivity to certain sounds. He would plug his ears at sounds that would normally not bother another individual. Craig had a restricted diet, consisting mainly of white, bland foods.

Craig’s functional developmental capacities were not at the appropriate level for a high school student which caused him great difficulty at school. Craig preferred

solitary activities at home and spent the majority of his time playing fantasy-based video games and rereading science fiction books. Craig was capable of attending to and engaging with others, but this interaction was usually quite awkward. He experienced great difficulty regulating certain behaviors such as the desire to interrupt someone with a pedantic description of an off-interest topic. Craig's pedantic speech, focused on topics such as Star Wars films, limited his capacity to engage in meaningful reciprocal social interaction. Craig used little gestural communication when engaged with others, not what one would expect from a freshman in high school. Craig's capacity for academic problem solving and logical thinking in mathematics was near grade level when he had sufficient support organizing his work. However, social problem solving was essentially absent and he had great difficulty with essay type assignments.

Craig's grades were average; however, he required substantial support from teachers and tutors. Craig had a compulsion to tell and write fictional stories, but this ability was limited by a rigid focus upon topics he had previously internalized such as the story line of a video game. Craig was trusting of others to the point of gullibility. His interactions with family members were warm and trusting, but his social awkwardness made it nearly impossible for him to form similar relationships outside the family unit. Part of Craig's problem in forming relationships stemmed from the manner in which Craig responded to others. He used one-word answers, or quips, that were devoid of personal connection with the topic at hand. These quick retorts were frequently used as a springboard for a pedantic description of his topic of interest: "HEY! By the way, when the Star Fleet Commander finds the secret location of the Death Star...."

Craig's parents expend considerable effort to provide him with a warm, stable home environment. They recognize Craig's concrete, literal form of thinking and use this throughout his development to teach him to follow rules. Rules help Craig avoid undue influence from his peers, and they are used to improve his social skills. For example, Craig was taught not to interrupt others who are talking. Craig's mother is an engaging, warm woman who is at home and makes herself very available to him. She spends considerable time planning and bringing him to activities, such as tutoring sessions for school, therapy sessions, and school activities.

Craig's family, including two siblings, is close, and they make a point of spending time together. They frequently plan weekend activities together and the entire family enjoys science fiction shows. Craig also took two trips with his dad in the past few years.

Despite these efforts, Craig spends most of his free time at home reading, playing video games, and watching television. His mother encourages him to participate around the home walking the dog, playing with his siblings, and exercising on an exercise machine, but like many such kids Craig is drawn to solitary, sedentary activities.

As part of the DIR intervention, Craig receives support at school from an educational therapist. This is provided by a woman with long experience in tutoring children with special needs, including autism spectrum disorders, in academic

subjects. She is adept at problem-solving social difficulties within the school setting. For example, she used video taped feedback to help Craig realize how disruptive his behavior could be in the classroom. Craig also participates in speech therapy which he has on and off from early childhood.

Craig has participated in sessions with the graduate student for 20 months to date. Sessions occur one day a week and last approximately four hours. He also sees his psychiatrist every other week to work on engagement and reciprocity and for case management of the entire multi-modal DIR intervention. The office-based sessions have continued as one component of a multi-modal DIR intervention.

## **Forming a Relationship**

Craig's sessions with his interventionist provide him with an opportunity to engage in activities that most adolescents his age enjoy. They head out on the weekend to do sports and go to amusement parks and burger joints. These sessions focus on Craig's ability to participate appropriately in these activities and to improve his social skills in general. Initial sessions slowly built Craig's sports skills and interpersonal rapport. One month into the intervention a pivotal event occurred which secured the school's desire to have him to return for a second year. Students were very interested in whether Craig would attend the prom. He wanted to go, but his caretakers felt this should not occur without close supervision. The school allowed Craig to attend the prom accompanied by his interventionist. Before the prom, Craig and the interventionist discussed the specifics of how a prom works and how he might enjoy the prom while being socially appropriate.

By prom time the two of them were excited and ready to enjoy the activity. Craig was engaged and enthusiastic the entire evening, and his classmates took him under their care. Craig spent the majority of his time talking and dancing with classmates. This is not to say that Craig metamorphosed in a single evening. He derailed some conversations by discussing Star Wars. Still, he was the center of attention at his small prom because everyone was so surprised that he was there and doing well. A female classmate even invited him for a slow dance, which he enjoyed. The interventionist provided Craig with an opportunity he would have otherwise missed. The preparation worked well and the prom showed Craig that social activities can be truly enjoyable. In fact, the interventionist did little once they were at the prom itself. That evening changed the way his peers treated him for several weeks until the summer break and increased his awareness of, and ability to engage in, a world that is dependent upon interaction with others.

Craig learned about the world, friends, and how to be with people in the context of his relationship with the interventionist. When Craig made a corny joke in the car, the interventionist would playfully threaten to pull over at the tomato fields near his house to pelt him with tomatoes. Craig would laugh and think about what he said and he understood that he'd gone a little too far. It was this kind of interaction that

helped Craig learn when his jokes were bad, not a didactic rule but a more complex and subtle appreciation of gestural context and communication.

Much of the early intervention was spent this way building specific physical and social skills Craig lacked. While playing sports such as basketball, baseball, and golf, the interventionist helped Craig improve coordination and learn specific rules of the game. Craig's experience in athletics was severely limited, and his fine and gross motor skills were poor. Craig was large and heavy set and had little stamina. He made real progress relatively quickly. This occurred in the context of a growing and warm friendship between Craig and the interventionist.

They often had lunch at a sandwich shop or burrito joint and talked about proper diet and the happenings of the week. Initially, Craig's comments centered on video games and movies and his speech was pedantic. He talked in obsessive detail about new levels he reached in a game or a scene of a movie he had seen. This style of interaction impeded most discussions he had with people, and his interventionist worked at making him aware of this. Gradually, this highly compulsive behavior diminished as the interventionist shared with Craig his own distaste for it and the potential for this pedantic speech to jeopardize his relationships with peers.

The following interaction illustrates one example of the process by which the interventionist guided Craig towards understanding and redirecting his pedantic style of speech:

*Craig*—"Would you like to hear about the latest developments in Episode I?"

*Interventionist*—"No, thanks. I'm not that interested in Star Wars."

*Craig*—"Well Anakin Skywalker is just a boy when the movie begins and...."

*Interventionist*—"Craig! You're killing me! You just asked me if I want to hear it, and you're still telling me, even though I said 'no'."

*Craig*—"Sorry, I just can't help myself."

*Interventionist*—"Well, let's see if you can. Maybe if you could share with me a couple of facts, I'd be willing to listen to Star Wars."

*Craig*—"I have this new game on my mom's PC. There's this ship called the Eclipse. It can hold one hundred thousand storm troopers, three hundred Imperial walkers, and it has one thousand.."

*Interventionist*—"There. That's where you stop. For someone like myself who's not that interested in Star Wars, that is about how much I'm willing to hear. Anymore than that and it drives me nuts! I start to tune out."

As pedantic speech diminished, more opportunity arose to discuss various social graces. Craig's interventionist provided him with feedback on his behavior. He spent a lot of time helping Craig to understand and change rigid and compulsive behaviors and to develop the patience required for both social discourse and more natural interaction. Craig was coached to resist the urge to interrupt someone even when he had something important to say. This required him to recognize this urge, regulate his behavior, and redirect himself to listen intently until the other person finished what they had to say. With less time spent in pedantic speech, Craig attempted to engage in a socially appropriate manner. Initially, this was very difficult for him. He

was not accustomed to listening to what others say, nor showing genuine concern for their feelings. The interventionist constantly pointed out to Craig what he was doing and how he could do it better. The two of them worked together in improving Craig's level of engagement. Craig's persistence and trust, both characteristic of his condition, were truly necessary for him to maintain engagement in the face of frequent corrections by the interventionist.

### **The First Major Shift in Craig's Functioning**

In the previous vignette (Troy), changes came in "leaps" and consisted of easily recognizable, specific behaviors. Craig's changes occurred more gradually and presented as something similar to phases. As Craig developed through different phases, his skills increased as did his overall level of functioning. Craig developed the ability to share with his interventionist important activities that occurred in the week since he had seen him. Craig's compulsion for describing things gradually shifted to more appropriate forms. Several months into the intervention instead of listing the specifications of a Star Wars vessel he listed the week's activities. His interventionist pointed this out to him and they worked on sharing his week in a "real" way. Not only did Craig learn to avoid describing his week in awkward detail, he also learned to share his life with others in a manner that provides a real connection between two individuals. Craig learned to enjoy connecting with someone and his pedantic style subsided to the point where mild reminders kept it largely in check.

Craig's progress in athletics paralleled his gains in the social realm. Just as with social interaction, Craig developed new skills that allowed him to enjoy an activity in an entirely novel fashion. While at first the interventionist coerced Craig into trying sports, Craig now suggested and looked forward to them. On the field, he learned specific techniques then thoroughly enjoyed the game. Indeed, the game for Craig was golf. Much like other sports, Craig had great difficulty the first few times he went to the driving range. Although hitting a stationary object was a more reasonable task for him than, say, hitting a baseball, he had a great deal of difficulty making contact between the head of the club and the ball. In time he developed this skill, and he learned other aspects of the game such as rules and which club to use for different shots. Craig played at the driving range and a 'pitch n' putt', which is a course where you never have to play more than 100 yards to a hole. After a few months of golf, his skills developed rapidly.

By this point in the intervention, Craig made the leap to playing on a real course and he loved it. At first, he merely went through the motions: he came to the course and gave it a shot, but he was not really in touch with the activity. Additionally, walking the course was a challenge the first few months of play, but gradually Craig's stamina improved enough that he did not complain.

Eventually, he learned to enjoy the entire game. He cheered when he made a good shot and he and his interventionist would exchange high-fives and talk strategy. After the game, they tallied the score over lunch and laughed about shenanigans on

the course. The foundation afforded Craig the opportunity to love the game and consider himself a golfer.

Golf was a useful tool for both Troy and Craig. Their skills improved to the point that both were considered to be decent golfers by any objective standard. A big part of golf is joining a 'foursome' often with people you do not know. This provided ample opportunity for social interaction with new acquaintances. Craig and his interventionist reviewed these interactions and worked on improving his skills in these situations. Specifically, Craig often cracked "corny" jokes and talked off topic. In time, he regulated this behavior, cracking truly funny jokes at appropriate times.

Craig's transformation was also evident in his second year of high school. Craig went from disturbing classes and not knowing names to becoming an active social participant in the school environment. The time he spent with his educational therapist had a profound effect upon his behavior in the classroom. He and his educational therapist reviewed videotapes of his classroom behavior and she guided him and worked on his ability to self-reflect. During his sophomore year, he did so well that educational therapy was cut from six hours per week to two. The school was eager to invite him back for another year.

The drastic change in the school's attitude made sense given Craig's sudden academic and social success. He brought home nearly straight "A" report cards, and he was at or above grade level in all of his classes. Although he did not receive occupational therapy he was tutored, especially in math, and the quality of his handwriting and organization on paper also improved. This was significant because just a year or two earlier Craig's difficulties writing on paper prevented academic progress. We think that the work Craig did with the graduate student outside of school contributed to his improved academic function.

Craig developed the interest and ability to navigate the social "jungle" of high school and a host of issues opened up during meetings with the interventionist. Craig learned that some people at school were teasing him while others were genuine friends. Teasing often took the form of classmates telling him ridiculous stories that he naively believed. In one instance, a classmate told him that she was pregnant and he believed this for days before learning the truth. Craig surprised his peers when he came back aware of their games and ready to appropriately defend or protect himself from additional teasing. For example, when a classmate told him she lost her purse that had \$5,000 in it, he said "whatever" and walked away.

Unlike other vulnerable kids, Craig had weekly educational and social support and guidance, which came from many different directions. He shared his school experiences with his mother, his educational therapist, his school counselor, his psychiatrist, and the graduate student interventionist. All of these individuals remained in close contact as part of a well-coordinated effort. Craig developed a curiosity for social behavior that surprised everyone who knew him. He frequently shared with his interventionist the romantic escapades of his classmates, arguments amongst his peers, and the good times he had or saw others having.

Craig's unbridled enthusiasm for social activity provided his interventionist with ample opportunity to guide him in the right direction and build various skills. Craig

learned to avoid unsavory situations, how not to be nosy, and how to build better relationships with classmates and faculty. Moreover, in his relationships with his intervention team, he developed the capacity for reciprocal concern, caring, and interest. At school, he needed to avoid some individuals as it was difficult to win their acceptance. He also taught Craig to generate discussions with others focusing on similar interests. This made his conversations with classmates less superficial or pedantic. While these relationships did not lead to out-of-school activities with these peers, Craig engaged them on a daily basis in some age appropriate banter.

### **The Latest Transformation**

Conversation between Craig and his interventionist changed drastically as he entered his third year of high school. Pedantic descriptions of the week's activities yielded to more fluid discussion between the two. Craig shared interesting and amusing stories, mainly about school, and they worked on Craig's affective connection to life events. For instance, when Craig casually told a story about a peer's anti-establishment ravings, the interventionist reacted with "Weren't you shocked? You don't sound shocked." Craig was shocked, and this exercise helped him figure out how to express the emotion. In a later installment of this on-going sub-plot at school, Craig was much more animated and clear in his retelling of the tale.

Craig grew in his ability to relate to others, and he then took great interest in the interventionist's life experiences. Craig asked what he had been up to and when the interventionist told him a story, Craig reacted with affective-laden responses.

Craig's new passion for athletics drove him to develop skills that further increased his enjoyment. In less than a year of playing golf, Craig could play on championship courses, and he played these courses well. Compliments from other golfers in his group were not uncommon. These comments were especially significant because they came from fellow golfers paired with Craig and the interventionist whom they had never met before. Craig initiated conversations with the entire group, often cracking pretty good jokes on the course. Craig's improved social and physical skills brought exciting experiences in other sports. Intervention sessions were no longer focused entirely upon rules and specific skill building. Craig engaged in real games of softball, basketball, and football with peers.

During Craig's junior year, he and his interventionist began small group sessions with another interventionist and his high-functioning companion with Asperger's disorder. These sessions helped Craig practice skills and build relationships in the presence of his interventionist. The interventionist then used these experiences to push Craig further in his development of normal peer relations. Craig had previously engaged with peers in activities outside school, and he put great effort and interest into forming friendships with his new companions. Sessions were spent in age appropriate activities such as sports, eating out, and amusement parks. Craig played and enjoyed football and basketball much like typical kids his age.

Craig put much effort into building relationships with his new companions. By this point in the intervention, Craig was very receptive to feedback from his graduate student and he used this feedback to work on his skills at interacting with the group. At first Craig's spontaneous interactions with group members were sparse, and his level of engagement in real games of basketball and football lacking. Initial sessions required a great deal of facilitation from the two interventionists. However, once these skills were strengthened in both Craig and the other adolescent and once the people got to know one another, the interventionists were able to pull back and engage as "ordinary" members of the group. After just five or six sessions of "learning" to have fun with the guys, Craig was cracking jokes, leading discussions, and competitively engaging in sports that he found intensely enjoyable. As a result, Craig was making the group laugh, generating interesting topics for discussion, and scoring touchdowns.

Craig approached a developmental level that was more consistent with what one might expect from a junior in high school, and he took interest in additional age-appropriate activities. Months before Craig's sixteenth birthday he talked about learning to drive. Craig and his interventionist worked on skill building with go-karts and golf-carts. Craig went into this "Driver's Ed" with the understanding that he would not obtain his license on his sixteenth birthday as he needed a great deal of training. However, he was still very interested in working towards this goal and he moved forward without becoming discouraged by his difficulties with spatial ability (including some small crashes). Occasional setbacks, such as running into a pole with a golf-cart, failed to deter his interest, and he continues to work on his driving skills with his interventionist. Craig also showed interest in potential career opportunities after high school. He took the Pre-SAT at school and talked with his interventionist about college, career, and living independently. Craig enjoyed discussing his passion for both writing and computers. He wrote lengthy fictional stories and took classes in computer programming offered in his community.

The group used Craig's thirst for science fiction to increase his connection and reciprocal interaction between he and the other adolescent with Asperger's disorder. This other young man has a penchant for drawing, and he and Craig teamed up to create a story with illustrations. These two had difficulty finding subjects in which they can generate a sustained interaction and the process of creating these stories provided them an opportunity to do so. They collaborated on two stories, totaling 80 pages of science fiction writing and animation.

Craig continued his remarkable academic progress during his junior year. His principal asked that he cease educational therapy all together, and faculty and staff thoroughly enjoyed his presence in the classroom. He excelled while taking college preparatory courses and maintained a nearly straight A average. Craig became one of the premier students at his private high school. Craig's peer relations improved greatly and he spent his junior year with minimal teasing or mistreatment from his classmates. This is not to say that Craig's social life was without difficulties as he and his interventionist worked every week on new challenges and sustaining the improvement generated in years of intervention. One new challenge was Craig's

growing attention to members of the opposite sex, including their antics, their appearance, and yet without a lot of understanding as to how those relationships work at his age. In fact, his understanding was much like that of a grade school child. The entire team worked to help Craig figure out what he thought about girls and how to respond to them. As it turns out, he was not particularly interested in dating per se, but he was open to the possibility in the future of dating, marriage, and having a family (a topic for an entirely different paper).

### **Craig in Perspective**

When Craig began work with his graduate student interventionist, he was 'high functioning' yet with severe limitations preventing him from normal peer relations and age appropriate behavior. With intervention he gained skills needed to relate to others, engage in age appropriate activities, and improve his affective connectedness to situations. He made leaps in some arenas, such as from simply hitting a ball to teaching his buddies how to play golf. When Craig was a high school freshman, we could not predict "mainstream" living in his future. Now he enjoys activities that many thought would never be possible, and he is on track for a fulfilling, productive, and likely independent life.

Craig learned about the subtleties of interacting with people. He appreciates what someone else is thinking and responds to that knowledge. He knows when his jokes are funny and when they will bomb. Craig's pride and self-confidence grew with the intervention. We think this was an internalization of the pride the interventionist showed in Craig's accomplishments. The afterglow of a golf shot well hit, amplified by the interventionist, became Craig's great moment.

### **Summary and Conclusion**

Children and adolescents are driven to be active. Their sense of self and relationships develop in this context. We understand that in our work our success is very much tied to our ability to use physical activity to help us truly engage the adolescents. This affective engagement, created through a relationship marked by physical interaction, made possible gradual gains in gestural communication, representational thinking, and theory of mind.

The aim of this article is to increase awareness of the efficacy of 'big brother' type interventions with children with autism spectrum disorders. This intervention has great utility. While these vignettes are limited to individuals on the autism spectrum, we also find it useful in fostering development, engagement, and building social skills in individuals we treat who have various forms of psychopathology, including anxiety, cerebral palsy, ADHD, and bipolar disorder. We suggest that the big-brother interventionist can be a very important part of a multi-modal approach to treating children and adolescents with various forms of psychopathology.

There are some notable limitations to the approach. It can be an expensive intervention. In Southern California, para-professional interventionists across many kinds of treatment modalities work for approximately ten dollars an hour, and those with more experience charge considerably more. Affording intensive intervention is a hefty expense for the typical family, especially considering that big brothers need to be supervised by a licensed clinician. In our area, some school districts are beginning to provide intervention services for children with autism spectrum disorders and regulatory disorders and the type of intervention discussed in this article could certainly be included as a component of these services. Additionally, the “real-world” environment in which these interventions are conducted can present risks. A whole host of factors come in to play when you remove a child from the safety of the home and conduct an intervention in an unpredictable social environment. The most notable “dangers” in our experience have been the children engaging in unpredictable behaviors which have the potential to harm them and other individuals.

Another possible limitation occurs when children or adolescents who are higher functioning reject the idea of someone coming to their home to “play” with them. These individuals strive to fit in and may reject this help if it is not carefully presented to them. In our experience, we have been able to woo most of these persons into a workable therapeutic relationship by giving careful consideration to the manner in which we present the relationship.

Additionally, boundary issues permeate this work. Using the client’s home as a location for intervention and bringing the client to different locations by car brings with it a host of potential problems. This difficulty is greatly alleviated by close supervision. The supervisor helps the ‘big brother’ gain the experience needed to appropriately handle potential boundary problems and to avoid potential pitfalls. With individuals on the autism spectrum, it is especially important to take care to present a relaxed yet well-mannered model. What we have found in our work is that if, in our lighthearted interactions, we ourselves are edging toward socially inappropriate behaviors, our clients will readily imitate them. This works against our goal of helping our patients function more seamlessly in the world around them. For example, while it is great to laugh about funny things that happen, scatological humor, often so affectively engaging, has with some kids become obsessive and problematic.

The interaction with parents has also been a potential boundary problem for interventionists. Several clinical issues can arise, such as triangulation, splitting, disclosures, and confidentiality. Careful supervision and training is a must. A very useful tool in such an intervention is an informed consent document which the interventionist requires the parents to sign. This form can be used to clarify the interventionist’s role and purpose and makes explicitly clear to the family that this individual is not a licensed clinician and that there is supervision by a qualified professional.

The last three years have been an extremely rewarding experience for both the interventionist and his supervisor. We have seen clients with a variety of psychological and developmental difficulties improve the quality of their lives. We are always working to improve our methods. For instance, the informed consent document for

the interventionist is a rather new development. We feel that such a system has great potential utility for children, adolescents, and adults, and we hope that this article will encourage others to try similar approaches.

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# FUNCTIONAL EMOTIONAL DEVELOPMENTAL QUESTIONNAIRE (FEDQ) FOR CHILDHOOD: A Preliminary Report on the Questions and their Clinical Meaning

**Jacob Greenspan and Stanley I. Greenspan, M.D.**

**Abstract:** *This report presents the questions that were formulated to profile an infant or child's functional emotional developmental capacities. As described in prior publications these capacities represent complex mental abilities associated with core areas of emotional and intellectual functioning. They are difficult to assess and therefore often insufficiently considered. In this report we present the responses to the FEDQ questions from a number of caregivers and compare it to brief clinical narratives as well as clinical ratings. We also look at the profiles for three groups of children, those with Autistic Spectrum Disorders, those with Regulatory Disorders and those functioning optimally. This preliminary report suggests the FEDQ has the potential to be a useful clinical tool when used in conjunction with a comprehensive evaluation and therefore further studies are warranted.*

In prior publications, we presented the functional emotional developmental model and approach to understanding emotional and intellectual development throughout the course of life (Greenspan, 1979; 1989;1992; 1997; Greenspan, DeGangi, & Wieder, 2001; Greenspan & Lewis, 1999; Greenspan & Salmon, 1993), along with rating scales and questionnaires for infancy and early childhood. In this article, we present the Functional Emotional Developmental Questionnaire (FEDQ) which extends into childhood and early adolescence.

To operationalize the Functional Emotional Developmental model, we developed the Functional Emotional Assessment Scale and carried out reliability and validity studies (Greenspan et al., 2001). The Functional Emotional Assessment Scale covers the infancy and early childhood years and is based on observations of infant-child-caregiver interactions. We also formulated the Developmental Growth Chart and Questionnaire (Interdisciplinary Council on Developmental and Learning Disorders Clinical Practice Guidelines Workgroup, 2000). The Developmental Growth Chart is a clinical observation framework which covers infancy and early

childhood and is based on either direct observations, questions answered by parents, or both. In this article we present the Functional Emotional Developmental Questionnaire (FEDQ), which provides a way to obtain and conceptualize information about functional emotional developmental capacities during later childhood and early adolescence, as well as the infancy and preschool years. Like the FEAS, it provides a rating scale to help determine the degree of competency and dysfunction for each functional emotional developmental capacity. The FEDQ, however, is not an observational tool like the Functional Emotional Assessment Scale (FEAS), but a questionnaire that can be administered to parents. The FEDQ can complement the FEAS or be used on its own. It can also serve as a framework to guide observation and conceptualize impressions of emotional and intellectual functioning up through later childhood and early adolescence. Because it focuses on functional emotional developmental capacities, it can also be used with older adolescents and adults whose functional emotional developmental capacities do not extend beyond an early adolescent level.

This is a preliminary communication presenting the questionnaire, its application to a number of cases, and some preliminary descriptions of its potential for being a reliable and valid approach. Future reliability and validity studies, however, will be needed to determine this. The goal of this communication is to foster further research and observation.

The Functional Emotional Developmental model was originally formulated from an integration of developmental models dealing with in depth emotional functioning, social, and cognitive development (Greenspan, 1979; 1989). The model was also informed by empirical studies of normal development and clinical observations and work with infants and children with clinical challenges, including those associated with multi-problem families, biologically-based developmental disorders, and a variety of behavioral, emotional, and learning problems (Greenspan et al., 1987; Greenspan, 1992; Greenspan & Wieder, 1998).

The Functional Emotional Developmental model was created to deal with challenges that other approaches to emotional functioning had not sufficiently dealt with. For example, the deeper levels of emotional development are not easy to observe and conceptualize, let alone rate. Most tools focus on a narrow feature of emotional functioning and may not capture important deeper developmental elements, such as the depth of the capacity for intimacy, the ability to experience at different functional levels the full range of emotional themes, including dependency, pleasure, sexuality, assertiveness, anger, and the capacity to understand and reflect on these complex feeling states in oneself and others (Greenspan et al., 2001). Also, many approaches do not sufficiently deal with the individual sensory processing and motor planning differences or the integration of affective, cognitive, motor, and sensory processes involved in emotional functioning (See Chapter 4 of Greenspan, et al., 2001).

The FEDQ is based on the Functional Emotional Developmental model, which conceptualizes the major emotional, social, and intellectual tasks that characterize human development including surface and in-depth elements during each of its stages from infancy into the adult years. This model is unique in that it not only looks

at emotional development, it also focuses on how one's emotional organization orchestrates the other facets of development into an integrated pattern. For example, it formulates how the eight-month-old emotionally expresses its emotional needs to caregivers in a purposeful, two-way (reciprocal) manner and, in so doing, also organizes cognitive, motor, sensory, language, and social capacities. Two-way emotional signaling identifies the child's cognitive ability for cause-and-effect interactions, his motor ability to make purposeful actions, his sensory processing capacities, including visual-spatial processing, to make sense of other people's gestures and facial expressions, his language capacities for exchanging vocalizations, and his social capacities to form, sustain, and negotiate a relationship. In this model, at each stage in human development, emotional capacities can be seen to orchestrate a wide range of related mental abilities. The Functional Emotional Developmental approach has been described in some detail (Greenspan, 1989; 1992; 1997; Greenspan et al., 1999; Greenspan & Salmon, 1995) and is summarized in Tables 1 and 2. Table 1 provides an overview of the stages of functional emotional development and Table 2 describes a framework to operationalize the range and degree of mastery possible at each stage.

**Table 1: Overview: Stages of Functional Emotional Development**

| <b>Developmental Level</b>   | <b><i>Emotional and Social Skills</i></b>   |
|--|---|
| Shared attention and regulation                                      | Affective interest in sights, sound, touch, movement and other sensory experiences. Also, initial experiences of modulating affects (i.e., calming down)  |
| Engagement and relating  | Pleasurable affects characterize relationships. Growing feelings of intimacy.   |
| Two-way intentional communication                                    | A range of affects become used in back-and-forth affective signaling to convey intentions (e.g., reading and responding to affective signals)   |
| Complex, problem-solving gestures. Organization of presymbolic self. | Affective interactions organized into action or behavioral patterns to express wishes and needs and solve problems (showing someone what you want with a pattern of actions rather than words or pictures) <ol style="list-style-type: none"> <li>a. Fragmented level (little islands of intentional problem-solving behavior)</li> <li>b. Polarized level (organized patterns of behavior expressing only one or another feeling states, e.g., organized aggression and impulsivity or organized clinging, needy, dependent behavior, or organized fearful patterns).</li> <li>c. Integrated level (different emotional patterns—dependency, assertiveness, pleasure, etc.—</li> </ol> |

**Table 1:** (Continued)

| <b>Developmental Level</b>                                  | <b><i>Emotional and Social Skills</i></b>   |
|---|---|
|   | organized into integrated, problem-solving affective interactions such as flirting, seeking closeness, and then getting help to find a needed object)   |
| Creating representations (or ideas)                         | <ol style="list-style-type: none"> <li>1. Words and actions used together (ideas are acted out in action, but words are also used to signify the action).</li> <li>2. Somatic or physical words to convey feeling state (“My muscles are exploding,” “Head is aching”)</li> <li>3. Putting desires or feelings into actions (hugging, hitting, biting)</li> <li>4. Using action words instead of actions to convey intent (“Hit you!”)</li> <li>5. Conveying feelings as real rather than as signals (“I’m mad” “Hungry” “Need a hug” as compared with “I feel mad” or “I feel hungry” or “I feel like I need a hug”). In the first instance, the feeling state demands action and is very close to action and in the second one, it’s more a signal for something going on inside that leads to a consideration of many possible thoughts and/or actions.</li> <li>6. Global feeling states (“I feel awful,” “I feel OK,” etc.).</li> <li>7. Polarized feeling states (feelings tend to be characterized as all good or all bad).</li> </ol> |
| Building Bridges Between Ideas: Thinking                    | <ol style="list-style-type: none"> <li>1. Differentiated feelings (gradually there are more and more subtle descriptions of feeling states—Logical loneliness, sadness, annoyance, anger, delight, happiness, etc.).</li> <li>2. Creating connections between differentiated feeling states (“I feel angry when you are mad at me.”)</li> </ol>   |
| Multiple-Cause and Triangular Thinking                      | Triadic interactions among feeling states (“I feel left out when Susie likes Janet better than me”).  |
| Gray-Area, Relativistic Thinking                            | Shades and gradations among differentiated feeling states (ability to describe degrees of feelings around anger, love, excitement, love, disappointment—“I feel a little annoyed.”)   |
| Reflective thinking with an internal standard—sense of self | Reflecting on feelings in relationship to an internalized sense of self (“It’s not like me to feel so angry.” Or “I shouldn’t feel this jealous.”).   |
| Extended reflective thinking into adolescent years          | <ol style="list-style-type: none"> <li>1. Expanding reflective feeling descriptors into new realms, including sexuality, romance, closer and more intimate peer relationships, school, community, and culture, and emerging sense of identity (“I have such</li> </ol>  |

**Table 1:** (Continued)

| <b>Developmental Level</b>                    | <b>Emotional and Social Skills</b>  |
|---|---|
| Extended reflective thinking into adult years | an intense crush on that new boy that I know it's silly. I don't even know him.”).  |
|   | 2. Using feelings to anticipate and judge (including probabilizing) future possibilities in light of current and past experience (“I don't think I would be able to really fall in love with him because he likes to flirt with everyone and that has always made me feel neglected and sad.”). |
|   | Expanding feeling states to include reflections and anticipatory judgment with regard to new levels and types of feelings associated with the stages of adulthood, including  |
|   | a. intimacy (serious long-term relationships)   |
|   | b. ability to function independently from, and yet remain close to and internalize many of the positive features of, one's nuclear family   |
|   | c. the ability to nurture and empathize with one's children without over-identifying with them  |
|   | d. the ability to broaden one's nurturing and empathetic capacities beyond one's family and into the larger community   |
|   | e. the ability to experience and reflect on the new feelings of intimacy, mastery, pride, competition, disappointment, and loss associated with the family, career, and intra-personal changes of mid-life and the aging process.   |

**Table 2: Overview of the Levels of Thinking and the Different Degrees of Mastery Possible At Each Level**

| <b>Self-Regulation and Interest in the World (Homeostasis)<br/>(first learned at 0-3 months)</b>                                       |  |  |   |
|--|--|--|---|
| <b>1 - Maladaptive</b>   | <b>3</b>   | <b>5</b>   | <b>7 - Adaptive</b>   |
| Attention is fleeting (a few seconds here or there) and/or very active or agitated or mostly self-absorbed and/or lethargic or passive | When very interested or motivated or captivated can attend and be calm for short periods (e.g., 30 to 60 seconds). | Focused, organized, and calm except when overstimulated or understimulated (e.g., noisy, active, or very dull setting); challenged to use a vulnerable skill (e.g., a child with weak fine motor skills asked to write rapidly), or ill, anxious, or under stress. | Focused, organized, and calm most of the time, even under stress. |

**Table 2:** (Continued)

| <b>Forming Relationships, Attachment, and Engagement<br/>(first learned at 2–7 months)</b>   |  |  |  |
|--|--|--|--|
| <b>1</b>   | <b>3</b>   | <b>5</b>   | <b>7</b>   |
| Aloof, withdrawn, and/or indifferent to others   | Superficial and need-oriented, lacking intimacy.   | Intimacy and caring is present but disrupted by strong emotions, like anger or separation (e.g., person withdraws or acts out).  | Deep, emotionally rich capacity for intimacy, caring, and empathy, even when feelings are strong or under stress.  |
| <b>Two-Way Purposeful Communication (Somatopsychological Differentiation)<br/>(first learned at 3–10 months)</b>   |  |  |  |
| <b>1</b>   | <b>3</b>   | <b>5</b>   | <b>7</b>   |
| Mostly aimless, fragmented, unpurposeful behavior and emotional expressions (e.g., no purposeful grins or smiles or reaching out with body posture for warmth or closeness). | Some need-oriented, purposeful islands of behavior and emotional expressions. No cohesive larger social goals.   | Often purposeful and organized, but not with a full range of emotional expressions (e.g., seeks out others for closeness and warmth with appropriate flirtatious glances, body posture, and the like, but becomes chaotic, fragmented or aimless when very angry). | Most of the time purposeful and organized behavior and a wide range of subtle emotions, even when there are strong feelings and stress.  |
| <b>Behavioral Organization, Problem-Solving, and Internalization (Complex Sense of Self) (first learned at 9–18 months)</b>  |  |  |  |
| <b>1</b>   | <b>3</b>   | <b>5</b>   | <b>7</b>   |
| Distorts the intents of others (e.g., misreads cues and, therefore, feels suspicious, mistreated, unloved, angry, etc.)  | In selected relationships can read basic intentions of others (such as acceptance or rejection) but unable to read subtle cues (like respect or pride or partial anger). | Often accurately reads and responds to a range of emotional signals, except in certain circumstances involving selected emotions, or stress or due to a difficulty with processing sensations, such as sights or sounds, e.g., certain signals are confusing.      | Reads and responds to most emotional signals flexibly and accurately even when under stress (e.g., comprehends safety vs. danger, approval vs. disapproval, acceptance vs. rejection, respect vs. humiliation, partial anger, etc.). |

**Table 2:** (Continued)

| <b>Representational Elaboration and Differentiation<br/>(first learned at 18–48 months)</b>   |  |  |   |
|---|--|--|---|
| <b>1</b>  | <b>3</b>   | <b>5</b>   | <b>7</b>  |
| Puts wishes and feelings into action or into somatic states (“my tummy hurts”). Unable to use ideas to elaborate wishes and feelings (e.g., hits when mad, hugs or demands physical intimacy when needy, rather than experiencing idea of anger or expressing wish for closeness) | Uses ideas in a concrete way to convey desire for action or to get basic needs met Does not elaborate idea of feeling in its own right (e.g., “I want to hit but can’t because someone is watching” rather than “I feel mad”). | Often uses ideas to be imaginative and creative and express range of emotions, except when experiencing selected conflicted or difficult emotions or when under stress (e.g., cannot put anger into words or pretend).         | Uses ideas to express full range of emotions Is imaginative and creative most of the time, even under stress.   |
| <b>Emotional Thinking</b>   |  |  |   |
| <b>1</b>  | <b>3</b>   | <b>5</b>   | <b>7</b>  |
| Ideas are experienced in a piecemeal or fragmented manner (e.g., one phrase is followed by another with no logical bridges).  | Thinking is polarized, ideas are used in an all-or-nothing manner (e.g., things are all good or all bad. There are no shades of gray).   | Thinking is constricted (i.e., tends to focus mostly on certain themes like anger and competition). Often thinking is logical, but strong emotions, selected emotions, or stress can lead to polarized or fragmented thinking. | Thinking is logical, abstract, and flexible across the full range of age-expected emotions and interactions. Thinking is also relatively reflective at age-expected levels and in relationship to age-expected endeavors (e.g., peer, spouse, or family relationship). Thinking supports movement into the next stages in the course of life. |
| <b>Triangular and Multi-Cause Thinking (Reflective)</b>   |  |  |   |
| <b>1</b>  | <b>3</b>   | <b>5</b>   | <b>7</b>  |
| Unable to be logical. Tends to get fragmented or piecemeal where logical bridges between ideas are lost.  | Can be logical, but only in a concrete manner and is unable to reflect on multiple reasons and indirect influences for age-expected experience.  | Can reflect on multiple reasons and feelings and consider indirect influences for some age-expected experiences, but not others (e.g., for competition, but not closeness and intimacy). Cannot be reflective in this way      | Can think about and reflect on multiple reasons for feelings for age-expected experiences. Can look at indirect influences (e.g., “She is upset because she is mad at her parents, not me.”). Age-expected experi-  |

**Table 2:** (Continued)

| <b>Affectively Differentiated (Gray Area) Reflective Thinking</b>  |  |   |   |
|--|--|---|---|
| <b>1</b>   | <b>3</b>   | <b>5</b>  | <b>7</b>  |
| Unable to be logical. Tends to get fragmented or piecemeal or very polarized in thinking.  | Can be logical, but only in a concrete manner, and cannot reflect on multiple reasons and indirect influences for age-expected experience.   | Can reflect on multiple reasons and feelings and consider indirect influences for only some age-expected experiences and events and not when feelings are very strong.  | ences would include experiences would include experience with parents, siblings, peers, school, and a full range of feelings from dependency to curiosity and anger and loss.<br><br>Can reflect on varying degrees of different feelings for a range of age-expected experiences or events (e.g., "I feel a little angry, but mostly disappointed that Dad forgot his promise."). Age-expected experiences would include experience with parents, siblings, peers, school, and a full range of feelings from dependency to curiosity and anger and loss. |
| <b>Reflective Thinking Based on Internal Sense of Self and Standards</b>   |  |   |   |
| <b>1</b>   | <b>3</b>   | <b>5</b>  | <b>7</b>  |
| Unable to reflect on multiple causes or engage in gray-area thinking, is sometimes logical in only a concrete manner or becomes polarized or fragmented in thinking. | Can be reflective and consider multiple causes and engage in gray-area thinking, but is unable to simultaneously reflect on moment-to-moment experiences and an inner standard or sense of self. | Can reflect on feelings or experiences of the moment and, at the same time, compare them to a longer-term view of themselves and their experiences, values, and/or goals or ideals for some age-expected experiences, but not others (i.e., with peers, but not with parents or with the closeness, but not with anger). Cannot be reflective in this way when feelings are strong. | Can reflect on feelings or experiences of the moment and, at the same time, compare them to a longer-term view of themselves and their experiences, values, and/or goals or ideals. Can be reflective in this way across the full range of age-expected experiences, and in the context of new cognitive capacities (i.e., for probabilistic, future oriented thinking).*   |

Up to now, we have not had a questionnaire that could be used with parents regarding their school-aged children, adolescents, or adults (who are functioning at an earlier adolescent developmental level) to identify the person's relative mastery of each of the functional emotional developmental capacities. Therefore, we formulated the FEDQ. In this article, in addition to describing the Functional Emotional Developmental Questionnaire, we describe its relationship to direct observations of children's functional emotional developmental capacities during interactions with caregivers. We also describe the different patterns observed for three groups of children—one with an optimal level of competence, a second with regulatory problems, and a third with a diagnosis of an autistic spectrum disorders (PDD patterns).

### **The Development of the FEDQ**

The main challenge in developing a Functional Emotional Developmental Questionnaire was to capture the complexity of the developmental process from infancy through the early adolescent years with relatively straightforward and easy-to-answer questions. The questionnaire was developed through numerous discussions, trial-and-error applications, and comparisons to videotape observations. As will be described below, in most instances, the answers to the straightforward questions were quite similar to direct observations that assessed the same functional emotional developmental capacities. In addition, two raters were quite similar in their clinical observational rating of eight of the cases. Furthermore, the parents' responses on the FEDQ, as were the clinical ratings, were quite different for three groups of children—children who were optimally competent, children with regulatory problems, and children with autistic spectrum (PDD) disorders.

Attempting to capture complex developmental processes with questions is a formidable challenge. Therefore, in this article, we only present and describe the questionnaire and the observed patterns. We deliberately do not include statistical analysis. The goal is to maintain a preliminary descriptive focus to create the basis for future studies.

See Appendix 1 for a description of the FEDQ. See Table 2 for a description of the clinical rating scale used to rate the Functional Emotional Developmental Capacities used in the comparison between FEDQ ratings and direct clinical observation.

The next sections will present brief narratives of a number of cases along with their clinical and FEDQ ratings, a description of the relationship between FEDQ patterns and clinical ratings of videotapes as well as a description of the FEDQ patterns and clinical videotape ratings for three groups of children—children with autistic spectrum disorders, children with severe regulatory disorders, and children with optimal patterns of development.

## **Making Sense of the Numbers**

The reader will observe that as we present a box with the results of the FEDQ at the end of each case study and in the tables that follow the case studies there are sometimes six, sometimes seven and sometimes as many as nine FEDQ question areas (ie., for functional emotional developmental levels) profiled. As can be seen in Appendix 1 the FEDQ parallels the hierarchy of functional emotional developmental capacities. For each capacity however, there may be one or a few questions, each rated on a seven point scale. Where there are multiple questions for a capacity letters (such as a, b, c, d, etc.) are used for each question so that the symmetry between the functional emotional developmental level and the number used next to the question is maintained. For example, Question 1 or Level 1 always refers to Regulation, Attention and Interest in the World. Question 2 and Level 2 always refers to Engagement, and so forth. The first six question areas and levels characterize the basics, dealing with Regulation and Engagement up to Building Logical Bridges between Ideas. Questions and Levels 7, 8 and 9, deal with more advanced reflective thinking including multi cause thinking, grey area thinking and thinking off a sense of self and internal standard. The FEDQ results for the more advanced reflective levels of thinking are only reported for those children who evidence competencies at the fifth and sixth level and are old enough to be expected to progress into the higher levels. (See the Questionnaire in Appendix 1 for further guidelines). Therefore, many children only have the first six levels profiled while some of the children also have level 7 and/or 8 and/or 9 profiled.

## **Section I—Case Illustrations**

To illustrate the usefulness of the questionnaire, a number of cases will be described below in terms of clinical notes taken at the time of the visit followed by the FEDQ and clinical ratings. This will enable the reader to see how closely the questionnaire (as well as the clinical ratings) capture the narrative.

### ***Case Study—Sam***

Sam came into my office today after a four year hiatus. When he came the last time, he had some words, but tended to get a little fragmented in using them. He could relate with real warmth and was beginning to work on putting words together in terms of building bridges between ideas.

At present, Sam is about age 8 $\frac{1}{2}$ , almost 9, and he came into my office able to engage with nice warmth and a happy smile. He was obviously very comfortable with both mother and father. However, he showed some challenges in a number of areas, some of them fundamental and some more advanced.

In the fundamental areas, Sam had a hard time gesturing to show his needs and wants, let alone using words, in long back-and-forth conversations. For example, he

didn't have the ability to interact with 50 circles of communication in a row with sounds, hand gestures, using a picture, or using his words. He didn't participate in the rhythm of a conversation. While it has been hard for Sam to learn this skill, he also has not had enough practice in it. Therefore, the school, the people who work with Sam at home, additional helpers, and mother and father need to work hard on helping Sam practice long back-and-forth sequences of interaction and conversation.

When the parents were trying to talk with him, Sam sometimes looked at them with a smile, but without understanding what was being said. I encouraged the parents and others to make sure they had him engaged in a back-and-forth rhythm of conversation, being careful to get his responses and making sure he understood what was said to him.

When Sam was really engaged and pulled into interaction with another person, he could sequence his ideas and problem-solve. He could also use more words when he was engaged. However, when he was not engaged and pulled in, he didn't have a big range of words and ideas he could use. As Sam becomes more engaged in back-and-forth interaction, I recommend taking him to different places to expand the range of ideas he can use.

In terms of building bridges between ideas, Sam could answer 'where' and 'what' questions, but was weak in his ability to answer "why" level questions. It's important to strengthen his skill at answering "why" questions because this will teach him to think in terms of cause and effect. To help him, his family and educators at school should find things he really wants, like books, and ask questions like "Why do you want the book?" when he reached for it.

Sam's scores on the FEDQ and through clinical observation follow.

|           | <b>Questionnaire</b> | <b>Clinical</b> |
|-----------|----------------------|-----------------|
| <b>1.</b> | <b>3</b>             | 3.5             |
| <b>2.</b> | <b>6</b>             | 5               |
| <b>3.</b> | <b>4</b>             | 4               |
| <b>4.</b> | <b>3</b>             | 3               |
| <b>5.</b> | <b>3</b>             | 3               |
| <b>6.</b> | <b>1</b>             | 1               |

As can be seen the questionnaire, clinical ratings and clinical narrative present a similar profile. Sam had moderate difficulties in all his basic capacities except for engaging where he was relatively strong. In addition, it can be seen that he was just beginning to learn to connect his ideas together in order to think logically.

The reader should look at the FEDQ in Appendix 1 and compare the ratings to the clinical narrative for each of the cases that follow. It will provide a useful way to become familiar with the questionnaire and observe, first hand, if the questionnaire accurately profiles the child. The authors impression is that it does. Later in the paper we present questionnaire profiles for children with Autistic Spectrum Disorders, Regulatory problems and optimal functioning. As will be seen, the profiles of children with ASD tend to reflect significant challenges in the basic capacities for regulation, engagement, purposeful communication and complex multi circle problem

solving interactions, as well as higher level creative and logical thinking skills. The children with optimal functioning tend to have a profile reflecting relative competencies throughout the profile. Children with regulatory problems tend to demonstrate a profile characterized by relative competencies in engagement, two way communication and complex multi circle interactive problem solving with mild to moderate difficulties in attention and regulation and the range and stability of higher level of logical and reflective thinking.

### ***Case Study—Grace***

Grace, who was almost four years old, came into my office with a history of having had pretty typical development until she was around 15 months of age. At that time she showed a regression and acquired words were lost. She became much more self absorbed and self-stimulatory and her activity levels increased. Some time later (closer to age two) an evaluation was done and Grace was given a diagnosis of PDD.

Grace presented in my office today with a range of capacities. If the parents or others elicited from Grace some real interest and motivation, it was possible to get her to focus and attend with them. If there was a very structured task or game, she could focus as well. However, when she was not challenged, she could give up easily. Sometimes she could persist and other times would give up. It depended on how motivated she was or how distracted she got.

Some of the time there was a real gleam in Grace's eyes and she would smile both signs of some mastery at this level of engagement and relating. She obviously loved her parents. Other times, however, she could tune other people out. To help her move forward in this area, I recommended that the parents join in with the toys or objects she was interested in, putting them on their heads or in their shirts, so that Grace would have to relate to them while she was playing.

The key to complex communication is combining many circles into a pattern. Grace could do this a tiny bit when she was motivated. She needed to be engaged as part of continuous flow all the time to help her master this level. Increasing the challenge around things that interest her will help in this regard.

Grace could do some pretend play, for example, with dolls in a dollhouse. She had organized ideas and could use some words purposefully and meaningfully. However, many of the words she used were repeats of the last things she heard. At this time, Grace didn't critically assess the word she used to see if it was the right word before she said it. She didn't have practice in this area yet. As her gesturing improves, however, she will begin to add on meaningful words. The parents can help with this by challenging her to make choices about the things she wants. "Do you want the blue or the red?"

Grace could build bridges and make connections between her ideas and those of others under some structured situations, but was not yet able to do it spontaneously and was unable to think causally (i.e., answer "why" questions). Really connecting ideas, however, means that she needs to understand what's being said more thor-

oughly. As more meaningful language occurs, Grace will work on more complicated communication and will improve at connecting ideas.

Contributing to Grace's challenges was the fact that she clearly had auditory processing and language problems. She also had some sensory modulation challenges and tended to be oversensitive to most sensations. However, she could also be a little underreactive to pain and movement (a pattern of mixed reactivity to sensation). Grace's visual-spatial skills were a little stronger and a relative strength for her. Motor planning and sequencing was also a challenge, as judged by her athletic skills and the way she held a pencil.

The results of clinical observation and the FEDQ follow:

|           | <b>Questionnaire</b> | <b>Clinical</b> |
|-----------|----------------------|-----------------|
| <b>1.</b> | <b>3</b>             | 3               |
| <b>2.</b> | <b>3</b>             | 3               |
| <b>3.</b> | <b>3</b>             | 3               |
| <b>4.</b> | <b>3</b>             | 2.5             |
| <b>5.</b> | <b>3</b>             | 2.5             |
| <b>6.</b> | <b>2</b>             | 2               |

### ***Case Study–William***

William was 2–2/3 years old when he came to my office and had a history of having had slightly delayed motor development. Otherwise, he seemed to be developing typically. However, at about 12 to 14 months of age, he began losing the words he had and did not develop the use of more words. He became a little more self-stimulatory, aimless, and random in his behavior at that time as well. William was diagnosed with a language disorder and then a pervasive developmental disorder or autism between ages 2 and 2½.

When I saw William in my office, he had a big range. He vacillated between aimless, self-stimming behavior, darting from place to place and only closing one or two circles of communication in a row (not using any signs or language) to the top of his range where he could focus for a little bit, complete 5 to 6 circles of communication in a row, look at his parents with real warmth, and flash a big smile. He could even use some ideas, for example, he fed the dolly a pretzel and gave it a kiss. We could see that William could operate as high as the level of using some ideas when he was properly motivated. At his optimal level, he could follow simple directions and understand simple phrases, use a few signs, and occasionally come out with a word or two.

Contributing to William's problems were auditory processing and language, motor planning and sequencing challenges (the ability to carry out multi-step actions), and sensory modulation (he was underreactive and sensory-seeking). In general, he was much stronger in visual-spatial capacities than in auditory and language abilities.

William's scores on the FEDQ and through clinical observation are below.

|           | <b>Questionnaire</b> | <b>Clinical</b> |
|-----------|----------------------|-----------------|
| <b>1.</b> | <b>3</b>             | 3               |
| <b>2.</b> | <b>3</b>             | 3               |
| <b>3.</b> | <b>3</b>             | 3               |
| <b>4.</b> | <b>2</b>             | 2               |
| <b>5.</b> | <b>3</b>             | 2.5             |
| <b>6.</b> | <b>1</b>             | 1               |

### ***Case Study—Steven***

Steven was just three years old when he came into my office and he had a history of having had pretty typical development, except that his motor milestones were a little slow (he walked at 15 months). Generally, he was doing very well, however. It had been recently noted in his preschool program that it was hard for Steven to interact with the other children as fully as others were interacting and, while he was quite verbal, it was hard for him to deal with the complexities of the social and physical environment.

In a one-on-one setting, like my office, Steven was very calm and regulated. He could focus and attend. Periodically, we saw that he could become a little bit preoccupied and detached from the interactions going on and he would lose his attention. When he was challenged, however, it was possible to pull him back into interaction with another person. In my office, as the parents were working with Steven, they were able to pull him in regularly.

Steven was a warm, sweet, loving child who was very engaged. The only limitation to that sense of engagement and connectedness was when he got preoccupied. During those times, he was still engaged, but his attention could shift away from people and onto his toys or what he was doing. He was always aware of where his parents were, however, and was quite connected to them.

Steven could exchange two-way gestures with another person to communicate his needs or desires, but needed to be engaged in a longer back-and-forth flow of communication. The goal was to keep him opening and closing circles as much of the time as possible. To do that, I recommended that the parents and others challenge him to get back into a back-and-forth interaction.

Steven could take his parents by the hand or point to show them things he liked and he could figure out how things worked. However, he needed more practice in taking the initiative, being purposeful, and following-through.

Steven could be imaginative, but he preferred to follow scripts he was familiar with. He could, however, be creative and respond to his parents' creativity. Here the key goal was to work for imagination, creativity, and innovation.

Steven could hold logical conversations and answer "why" questions about feelings, but sometimes he could also get a little scripted. I recommended that those working with Steven challenge him to think creatively and logically. When he would go off on a tangent, in terms of his thinking ability, or get fragmented (e.g., he would bring in things from left field), the parents needed to catch him on it playfully. "Hey,

first you were talking about juice and now we're talking about Oscar the Grouch. What happened?" Let him figure it out. If he couldn't explain, I recommended that the parents either help him make the connections with multiple choice questions or go on to something else after a little while of trying.

Steven also had challenges in dealing with aggression and conflict (in pretend play).

Contributing to Steven's challenges was the fact that he had some motor planning problems in both fine and gross motor areas. These areas were evaluated by an occupational therapist. We could see this partly in the fact that it was hard for him to throw a ball. In addition, his walking and balance were a little more tentative than one would like to see. In terms of fine motor skills, he was still fisting the pencil a bit, although he understood the concept of circles.

Steven could get sensory overloaded and was, at the same time, somewhat under-reactive. That meant that the parents and those working with him needed to work on pulling him into interaction without overloading him.

Steven's auditory processing and language skills were stronger than his abilities in visual-spatial thinking. The goal has been to strengthen his visual-spatial skills to meet the strengths of his auditory processing.

The results of clinical observation, compared to the FEDQ, on Steven follow.

|           | <b>Questionnaire</b> | <b>Clinical</b> |
|-----------|----------------------|-----------------|
| <b>1.</b> | <b>5</b>             | 5               |
| <b>2.</b> | <b>5</b>             | 6               |
| <b>3.</b> | <b>5</b>             | 5.5             |
| <b>4.</b> | <b>5</b>             | 5               |
| <b>5.</b> | <b>5</b>             | 5               |
| <b>6.</b> | <b>5</b>             | 5               |

### ***Case Study–Gabriel***

Gabriel could focus and attend, but could still get a little fragmented. When one worked with him, however, it was possible to sustain his attention. He was a very sweet and engaged child who could be purposeful and read gestures. However, he had a hard time sustaining this ability for purposeful gesturing for long periods of time. Gabriel could solve problems and sequence his thoughts and actions, but here, too, needed some help doing it continuously, particularly in sensory-overloading environments. He was able to label his feelings, but when feeling extreme feelings, while he used his ideas he also went into behavior discharge mode and had tantrums.

Gabriel was able to be logical and answer "why" questions and was even beginning to answer some comparative "why" level questions. He was much less fragmented than he used to be and was now more coherent, although he was still unable to answer, for example, why he felt a certain way fully, particularly when feeling intensely. Gabriel still fell back on tantrums and felt the need to give in to his impulses. Gabriel's capacities for triangular thinking and relativistic gray-area think-

ing were emerging and he evidenced them once in a while, but he was not yet at age-expected levels.

Gabriel had the most difficulty with these basics in sensory-overloading environments, such as school, and did far better at being logical and regulated with adults than with peers, with whom he got more fragmented in his thinking and social behavior.

Here are Gabriel's ratings from the FEDQ and clinical observation.

|           | <b>Questionnaire</b> | <b>Clinical</b> |
|-----------|----------------------|-----------------|
| <b>1.</b> | <b>7</b>             | 7               |
| <b>2.</b> | <b>7</b>             | 8               |
| <b>3.</b> | <b>6</b>             | 6               |
| <b>4.</b> | <b>6</b>             | 6               |
| <b>5.</b> | <b>6</b>             | 6               |
| <b>6.</b> | <b>6</b>             | 6               |
| <b>7.</b> | <b>3.5</b>           | 4               |
| <b>8.</b> | <b>4</b>             | 4               |

### ***Case Study–Daniel***

Daniel was five years old and had a history of pretty typical development. However, his parents noticed that he wasn't developing language and was beginning to self-stim and line things up between 14 and 18 months. At age two, he was diagnosed with PDD. He had been in programs through the county ever since, receiving speech and some occupational therapy as well as varying degrees of therapeutic support.

Sometimes when Daniel was calm, he could be focused, regulated, and open and close five or six circles of communication. Other times, however, he jumped around, waved his hands, and retreated into his own world. The goal was to keep him focused, calm, and interactive all the time.

Daniel was a very warm and sweet child with a gleam in his eye. He was very friendly and loved his mother and father. He was also affectionate and liked to sit on people's laps and he could seek other people out to be close. His engagement was a real strength, but he could retreat in his own world and couldn't maintain the connection.

Daniel could open and close five or six circles of communication in a row when we saw him. He would begin to gesture purposefully, but then would retreat into his own world. The goal at this level was to get him to open and close 50 to 60 circles of communication in a row.

Daniel could problem-solve, take his parents to show them things he wanted and find things. However, he didn't do this in a continuous flow of interaction with 50 or more circles in a row. He could use his ideas and repeat words and phrases. He would also respond to simple questions like "Where is the horsy going?" with "To the truck." He could count a little and identify parts of his body. Daniel could do a little

bit of pretend play, for example, putting the dolly on the horsy, but basically, he was at the early stages of using his ideas. However, he wasn't consistent enough at this level of using ideas as well as gestures (again, with 50 or more circles of communication in a row).

Daniel could build bridges between ideas a little bit, but he was only at the beginning of this stage. He could connect a few of his ideas logically intermittently, but not consistently. He couldn't yet answer "why" questions or the simple "w" questions on a regular basis.

Contributing to Daniel's challenges was the fact that he had an auditory processing and language difficulty. He also had motor planning and sequencing problems, particularly in fine motor areas, and he also had some sensory modulation challenge which caused him to seek sensation. At the same time, however, he was also a little bit oversensitive to noise, sound, and sometimes touch, so, in addition to craving sensation, he could get overloaded with it. Mostly, however, he was sensory-seeking. A relative strength for Daniel was his visual system, including visual memory and thinking. For example, he could fit puzzles well.

The results of Daniel's ratings are below.

|           | <b>Questionnaire</b> | <b>Clinical</b> |
|-----------|----------------------|-----------------|
| <b>1.</b> | <b>3</b>             | 3               |
| <b>2.</b> | <b>3.5</b>           | 3.5             |
| <b>3.</b> | <b>4</b>             | 3.5             |
| <b>4.</b> | <b>3.5</b>           | 3.5             |
| <b>5.</b> | <b>3.5</b>           | 3.5             |
| <b>6.</b> | <b>1</b>             | 1.5             |

### ***Case Study—Michael***

Michael was a 7-year-old 1<sup>st</sup> grader who was in a hearing impaired class in school. He came into my office a very warm and related child who was capable of great intimacy and closeness. Michael could also focus and attend, but tended to drift off into focusing on his toys unless the parents really energized up and interacted with him around his interests. However, if the parents interacted with him, he would focus on them and talk with them. Once engaged, he could sustain his attention for a reasonable period of time and even do some hard academic tasks.

Michael could gesture meaningfully and be purposeful and he could sequence and problem-solve. He could open and close many circles of communication in a row and was able to use ideas creatively. He could also be very imaginative. Michael was able to be logical and answer all his "w" questions, including "why" questions. However, he was not yet able to answer comparative "why" questions ("Why do you like this thing better than that thing?") and was not able to engage in multiple-cause abstract or relativistic, gray-area thinking. These skills are emerging, however, and delays are due to the challenges to his language.

Michael also had some unevenness in his ability to connect ideas together logically and could jump around from one idea to another, getting fragmented. However, this is a capacity that he was just learning to master and the fragmentation in thinking was not so much a disorder as it was a lag in appropriate development. With practice, he should master building bridges between ideas more fully over the next year.

Contributing to Michael's challenges were problems in language, although he was making good progress. He also had some motor planning challenges, although these were improving. Michael tends to be sensory overreactive and could easily get overloaded in a noisy, multi-person environment. When that happened, he would retreat into his own world or freeze, for example, when he had to give a talk in front of his class. Michael's auditory and visual memories are relative strengths and he was also showing some strengths in reading as well. He could use some more work on throwing and catching balls or beanbags and in various perceptual motor activities.

Michael's clinical and FEDQ ratings follow.

|           | <b>Questionnaire</b> | <b>Clinical</b> |
|-----------|----------------------|-----------------|
| <b>1.</b> | <b>5</b>             | 5               |
| <b>2.</b> | <b>6</b>             | 6               |
| <b>3.</b> | <b>6</b>             | 6               |
| <b>4.</b> | <b>6</b>             | 6               |
| <b>5.</b> | <b>6</b>             | 6               |
| <b>6.</b> | <b>5</b>             | 5               |
| <b>7.</b> | <b>4</b>             | 3               |

### ***Case Study—Ryan***

Ryan was 4<sup>1/2</sup> years old and came into my office with a history of having begun some visual self-stimming at around 15 months of age. At that time, he also lost some words he had been able to use and there was decreased eye contact. Eventually, he was diagnosed (at age 2<sup>1/2</sup>) with a pervasive developmental disorder.

Ryan could focus and attend very briefly if he was very motivated, but for the most part, he tended to like to move around the room in a seemingly aimless or random way and liked to involve himself in self-stimulatory activities. However, as stated, he could focus when he was motivated. For example, here in my office when he wanted his juice, he was willing to search for it and say the word "juice." He was also able to focus on the Cheerios his mother was hiding in her hands.

Ryan could engage briefly, but tended to quickly get lost in his own activities and in more random activity. He clearly felt affection, however, and liked to hug and kiss his mother and father.

Ryan could be briefly purposeful when strongly motivated, and, around searching for his juice, was able to participate in opening and closing five or six circles of communication in a row. Routinely, however, he tended to do only one, two, or three circles in a row. However, with his mother at the end of the session in my office,

Ryan was able to exchange warm grins, smiles, and frowns and his mother was able to keep that interaction going for seven or eight circles.

In terms of problem-solving, Ryan showed periodic abilities to organize a problem-solving sequence, for example searching in mother's hand for a Cheerio or behind her back for juice. Here, too, he had to be very motivated and could easily get absorbed in more random-seeming activities. In terms of ideas, Ryan was able to repeat the word "juice," and was able to feed the dolly some juice when we challenged him and showed him how to do it.

Ryan was not ready for combining ideas together, although he was repeating in a more random way things he heard on TV or in other settings.

Contributing to Ryan's challenges was the fact that he had severe auditory processing and language problems. He also had some motor planning and sequencing difficulties. His visual-spatial capacities were a little stronger than his language abilities although they were not age-appropriate.

Ryan evidenced some overreactivity to certain sounds, but was mostly underreactive and craved sensation. His FEDQ and clinical rating table follows.

|           | <b>Questionnaire</b> | <b>Clinical</b> |
|-----------|----------------------|-----------------|
| <b>1.</b> | <b>2</b>             | 2               |
| <b>2.</b> | <b>3</b>             | 3               |
| <b>3.</b> | <b>3</b>             | 2.5             |
| <b>4.</b> | <b>2</b>             | 2               |
| <b>5.</b> | <b>2</b>             | 2               |
| <b>6.</b> | <b>1</b>             | 1               |

### ***Case Study—Abby***

Abby was a nine-year-old girl when we observed her in my office. We saw that she had a number of strengths, but also some challenges. In terms of her ability to stay calm and focused, she was able to do that in a supportive one-on-one situation. She could discuss a variety of subjects, from schoolwork, to peers, to family, to her brother. She was able to do math and read, write, do memory tasks involving numbers, words, and spatial configurations, and be very cooperative.

The sign of challenge in these areas came when Abby thought she was going to fail or not do something well. Then she wanted to stop trying, got silly, escaped into make-believe with her animals, or used some other escape route. I was impressed by the fact that even though she got distracted because she was feeling she couldn't do something, in a supportive one-on-one situation, she could be cajoled back into doing the task. For example, in my office we were doing something new for her (fractions) and I was asking her about  $4/3$ ,  $5/3$  and  $6/3$ , something she hadn't had yet. These fractions didn't make sense to her because they were, "More than the whole pie."

I tried to see if Abby could learn something new. When I cajoled her, she learned the task, was happy she learned it, and was able to give me good answers. She

didn't think she was going to get the task, though, and used all her escapist plans to avoid the possibility of failing.

In terms of reading, I gave Abby some advanced material and was able to cajole her into reading it. Together we figured it out and she was able to stick with the task. For Abby, anxiety and fear are mediators in her challenges with distraction.

Abby had a good capacity for relationships. The fundamental capacity to be connected with others was present. She handled a new relationship with me very well. Later she was able share with me some deeper issues regarding her family. Her ability to make good connections and relationships with other people was a real strength for her.

Abby could read basic gestures, sequence, problem-solve, and understand patterns. She could also use her ideas creatively and logically, engaging in causal thinking. In terms of non-emotional areas, she was able to look for multiple reasons for things and even do some gray-area thinking.

However, when it came to the world of feelings, Abby had a hard time putting them into words—getting the feelings from the behavior-discharge level to the ideational level, where she could picture the feeling, reflect on it and look for multiple causes for the feelings and, thus, progress to higher levels. Abby had the cognitive tools to do this, but couldn't yet apply them to the emotional realm. This came up in numerous ways, for example, in how she felt about her brother. She could give descriptions of events and situations, but it was hard for her to say how others were feeling in those situations. This was an area she hadn't mastered yet, even though she had the capability to do it.

Abby had trouble with certain pivotal feelings. She didn't like to acknowledge weakness, vulnerability, loss, and disappointment. While she focused on her accomplishments, everything else got denied (either consciously or unconsciously). This was not atypical, but it was typical of a younger child. Abby needed help with the feelings of disappointment, anger, loss (especially loss), disappointment, and humiliation. For that reason, I recommended that those working with her set up a nurturing, warm setting to work on those feelings.

Contributing to some of Abby's challenges were difficulties in the way she processed information. She was very good at details but had a much harder time with big-picture thinking. She would get lost in the feeling of the moment, rather than look at all the things in the context of what had happened, what was happening, and what would happen tomorrow or further in the future. She liked detail and could report on facts, but not on the emotions around them. Abby had a harder time with executive functions in terms of planning and sequencing as well. This was related to challenges in big-picture thinking. Her frustration tolerance was not as high as it could be in terms of being patient when there was a delay. Some of her problems were due to difficulties in reflecting on feelings. In addition, Abby had some sensitivity to sound, which could be overloading for her.

In a general sense, Abby's strengths were in relating and being curious and clever. She could appreciate reality and separate reality from fantasy, but she had trouble with the flexibility of her personality in terms of age-appropriate coping

capacities (labeling and reflecting on her feelings and finding age-appropriate ways of expressing them and negotiating them in conflicts). She would escape or get polarized (all-or-nothing) in her thinking instead.

Abby was best described by her regulatory profile above. Her symptoms weren't defined by specific diagnoses. It was better to describe her in terms of her profile rather than placing her in a specific category. Generally, however, she could be described as having an anxiety disorder.

Here are her ratings both clinically and using the FEDQ.

|           | <b>Questionnaire</b> | <b>Clinical</b> |
|-----------|----------------------|-----------------|
| <b>1.</b> | <b>7</b>             | 6               |
| <b>2.</b> | <b>7</b>             | 7               |
| <b>3.</b> | <b>7</b>             | 6               |
| <b>4.</b> | <b>6</b>             | 6               |
| <b>5.</b> | <b>5.5</b>           | 5.5             |
| <b>6.</b> | <b>5.5</b>           | 5.5             |
| <b>7.</b> | <b>3</b>             | 3               |
| <b>8.</b> | <b>3</b>             | 3               |

### ***Case Study–Brian***

Brian was about 7<sup>1</sup>/<sub>2</sub> years old and was in a second grade class for children with processing problems. He could focus and attend, especially when he was doing imaginative play and talking about things that interest him. It's a little harder to talk about things he was not interested in, such as school work. While it was possible for Brian to stay focused in his behavior, his thinking could get somewhat fragmented.

Brian was a sweet and engaged child, who sometimes played on his own, handling both sides of a dialogue himself. Generally, though, even during those times, he was still engaged with his parents, although he could be somewhat self-absorbed.

Brian was almost always purposeful in his behavior, although his thinking, as indicated could be a little fragmented. He was very creative in his use of ideas and was developing a nice imagination, but he needed more help in broadening the themes that he could use. He liked to play many of the same themes over and over, but didn't develop them as deeply or richly as we'd like.

Brian was able to be logical, build bridges between ideas, and answer "why" questions causally. He could answer comparative "why" questions as well, which indicated that he was very bright. In terms of his logical, reflective thinking, Brian had very good potential. At the same time, however, he could still get fragmented in his thinking, somewhat like a four year-old. There was an odd juxtaposition with Brian in that he acted like a four- to five-year-old in some of his thinking and in his general level of with-it-ness, but he had the cognitive capacities of a seven to eight year-old child.

Contributing to Brian's challenges were difficulties in auditory processing (straight language) and the ability to hold ideas in his mind. He was making progress

in this area, but he needed more work. With his cognitive level of abstraction, we would have expected him to be able to operate at a higher level on a number exercises I used in my office. Because of his processing challenges, it was hard for Brian to support his basic intelligence.

Brian's visual memory skills were relatively easier for him and he was able to copy four out of five of the shapes I asked him to do. Searching and visual thinking were generally hard for him, but his visual memory was good. In addition, he had challenges in both fine and gross motor planning and sequencing, but these areas were getting stronger all the time. In addition, he was sensory overreactive and could be anxious, shy, and get overloaded with sensory input.

From a diagnostic point of view, Brian evidenced a Regulatory Disorder, characterized by the above profile. He would no longer be characterized as PDD or autistic spectrum because he was too related and creative. His scores on the FEDQ and through clinical observation are below.

|           | <b>Questionnaire</b> | <b>Clinical</b> |
|-----------|----------------------|-----------------|
| <b>1.</b> | <b>5</b>             | 5               |
| <b>2.</b> | <b>7</b>             | 6               |
| <b>3.</b> | <b>6</b>             | 6               |
| <b>4.</b> | <b>5.5</b>           | 5.5             |
| <b>5.</b> | <b>5.5</b>           | 5.5             |
| <b>6.</b> | <b>5</b>             | 5               |
| <b>7.</b> | <b>3</b>             | 4               |
| <b>8.</b> | <b>3</b>             | 3               |

### ***Case Study—David***

David, who was six years old, came in with a history of language challenges, rigidity in behavior, and problems controlling impulses. He could focus and attend nicely, except that he could also tune a person out and then it was hard to pull him back in. He was a little underreactive to sensation so it was easy for him to tune out. When the parents increased the energy in their voices, however, they could pull him into interaction more easily.

David was a very sweet and related child who was very comfortable with adults, but less so with peers. He could be purposeful and intentional and could open and close multiple circles of communication in a row, but he could also get distracted and tune other people out. To help him become more intentional all the time, I recommended getting a back-and-forth rhythm going with him in the interaction and play. This back-and-forth rhythm would be necessary to keep David engaged. If he tuned out, the parents could then energize up and challenge him to respond. David was a smart child, a good problem-solver, and could sequence, but he needed to be more involved in interactive, shared problem-solving—building things together with his father, for example.

David was creative, imaginative, could use ideas, and could label feelings. However, he needed to have more ideas to use in pretend play. Mother had a natural ability in pretend play and father liked to build things and solve problems, but both needed to do pretend play with their son and have lots of discussions using many ideas.

David was logical and could think causally, answering “why” questions and combining ideas together in various ways. When he tuned out, he could get fragmented in his thinking and not connect his ideas to others’ ideas.

While David had challenges in motor planning and sequencing, his fine motor areas were getting stronger. Visual-spatial thinking needed more work as well.

From a diagnostic point of view, David evidenced a Regulatory Disorder, with language and motor planning and sequencing difficulties, as described in the *Diagnostic Classification: 0–3*, published by ZERO TO THREE/National Center for Clinical Infant Programs, 1994. He did not have a Pervasive Developmental Disorder or autism for several reasons. He was very connected and creative in his use of ideas. He had a gleam in his eye and really enjoyed relationships. In addition, he could gesture and read signals. When he tuned a person out, it was more an attentional problem than a problem on the autistic spectrum.

|           | <b>Questionnaire</b> | <b>Clinical</b> |
|-----------|----------------------|-----------------|
| <b>1.</b> | <b>5</b>             | 5.5             |
| <b>2.</b> | <b>6</b>             | 5.5             |
| <b>3.</b> | <b>5.5</b>           | 5.5             |
| <b>4.</b> | <b>5.5</b>           | 5.5             |
| <b>5.</b> | <b>5</b>             | 5               |
| <b>6.</b> | <b>5</b>             | 5               |
| <b>7.</b> | <b>3.5</b>           | 3               |

### ***Case Study–Phillip***

Phillip, who was 13 years old, came in with his mother and stepfather. He had a history of marked learning disabilities, mood swings, and compulsive behaviors. When he came in he was taking Cylexia (20 mg per day) and Risperidol (.125 mg. twice a day).

Most prominent in Phillip’s history was slightly delayed motor development and auditory processing, motor planning and sequencing, and sensory modulation challenges. He lost his biological father as an infant and had in his mind a picture of his father having been shot. Surrounding that fact, he was preoccupied with themes of aggression. Phillip wanted to, for example, join the army as soon as he was older. He had also been challenged by being teased at school and had struggled with his processing difficulties since he began in school.

Phillip could partially focus and attend, but could be distracted by his own thoughts, which seem to come out of left field, or by something physical that he was fidgeting with. However, he could engage with real warmth and trust.

Phillip could be purposeful and read nonverbal gestures. He was actually quite sensitive, in spite of his processing problems, to interpersonal cues. However, he could also get overloaded by the gestures and cues and take them in a highly personalized way.

Phillip was partially able to sequence and problem-solve and close multiple circles of communication in a row, but was not able to sustain that ability in an age-appropriate manner. In this regard, he evidenced significant sequencing and planning (executive functioning) problems.

Phillip was able to use ideas and symbolize his feelings, talking for example, about angry, sad, and happy feelings. However, he did not show the range of expected feelings for a child his age. He was preoccupied with themes of aggression surrounding his biological father's death, being teased at school, and BB guns, pellet guns, and Swiss Army knives.

Phillip was able to build bridges between ideas and think logically, but was not able to reflect on his ideas nor build bridges between them in an age-expected manner. For example, he tended to polarize his thinking, thinking in all-or-nothing terms, rather than in shades of gray, and tended to look for one explanation for a thing rather than considering multiple-causes. He had also not yet fully internalized a sense of judgment or standards upon which to compare and reflect external events or his own thoughts. He needed to master these higher levels of reflective and abstract thinking in the world of his own emotions as well as in his academic and general life.

When Phillip got anxious, he tended to use developmentally early, rather than age-appropriate mechanisms. For example, around writing or other school tasks, he would become passive and avoidant. He used compulsive rituals as an attempt to overcome his anxiety. He became moody and had mood swings rather than forming integrated, stable patterns. Phillip also still evidenced some magical thinking, particularly around joining his biological father, whom he idealized.

In summary, Phillip had strengths in the area of relating and was basically a somewhat clever youngster, but his numerous processing difficulties, coupled with his experiences in life, had led to a more fragile ego structure with lots of developmentally early mechanisms.

Contributing to Phillip's challenges were problems in auditory processing and language. He also had motor planning and sequencing challenges, as well as sensory modulation challenges. Furthermore, when he would get overloaded and stressed, instead of shutting down and becoming cautious, he would become more irritable and active.

From a diagnostic point of view, Phillip evidenced a Regulatory Disorder (RD), as described in the *Diagnostic Classification: 0-3*, published by ZERO TO THREE/National Center for Clinical Infant Programs, 1994, with his profile as just described. His regulatory dysfunction included significant attentional, mood, and anxiety (including compulsive rituals) components.

|           | <b>Questionnaire</b> | <b>Clinical</b> |
|-----------|----------------------|-----------------|
| <b>1.</b> | <b>6</b>             | 5.5             |
| <b>2.</b> | <b>6</b>             | 6               |
| <b>3.</b> | <b>6</b>             | 5.5             |
| <b>4.</b> | <b>5</b>             | 5               |
| <b>5.</b> | <b>5</b>             | 5.5             |
| <b>6.</b> | <b>5</b>             | 5               |
| <b>7.</b> | <b>4</b>             | 4               |
| <b>8.</b> | <b>4</b>             | 4               |
| <b>9.</b> | <b>1</b>             | 1               |

### ***Case Study—Devon***

Devon was a 2<sup>1</sup>/<sub>2</sub> year old little boy with a history of having had a pretty good first year in terms of his development. He was saying “Daddy,” “Mommy,” and “Bye.” Then he lost the use of some words, and although he became more withdrawn, he retained affection for his mother. At 18 months of age, he had even more regression, with less looking and the beginning of some more repetitive behavior, for example, he started lining toys up. An evaluation at 28 months suggested either autistic spectrum disorder, according to a neurologist, or OCD and hyperactivity, according to the psychologist.

He started speech therapy and occupational therapy twice a week and also did auditory integration training.

Devon presented with a big range. At the top of his range, when he was really engaged, he could focus briefly, engage with big smiles, use purposeful gestures, do some problem-solving behaviors, like searching in a doll’s house for a hidden toy. He could use lots of single words, occasionally a phrase, and do things like count, stack his blocks, and count when he was stacking.

At home, his parents reported, he did even more, for example, counting backwards and occasionally memorizing a song. He loved to play with his sister, albeit more in parallel play, and he would play similarly with other children. The hardest thing for Devon to do in my office was to sustain his top level of functioning for a long period of time. He was “in and out”—engaged, but then becoming over-invested in his toys and tuning his mother out. That made it hard for him to get 10 or 20 circles of communication in a row going in back-and-forth interaction.

Generally, while Devon had some ability at each of the levels, he was also quite constricted in terms of being able to maintain each one consistently.

Contributing to Devon’s challenges were auditory processing and language problems. He also had some sensory modulation difficulty, tended to be sensory-craving and somewhat underreactive to sensation, and required a lot of energizing up. He needed some work in the fine motor area of motor planning and sequencing and he had some relative strengths in his visual-spatial understanding, as well as in some of his gross motor functioning areas.

|           | <b>Questionnaire</b> | <b>Clinical</b> |
|-----------|----------------------|-----------------|
| <b>1.</b> | <b>3.5</b>           | 3.5             |
| <b>2.</b> | <b>4</b>             | 4               |
| <b>3.</b> | <b>4</b>             | 4               |
| <b>4.</b> | <b>3</b>             | 3               |
| <b>5.</b> | <b>3</b>             | 3.5             |
| <b>6.</b> | <b>2.5</b>           | 2               |

### ***Case Study–Martin***

When Martin was evaluated, he was 16 months old. On that day, he was feeling sleepy and tired. He had been traveling for a few days and was off his cycle. Also, he was in a different environment. Although I was not seeing him at his best, between parent reports and observation, I got a picture of his current functioning.

There was very nice improvement in Martin's ability to focus and be engaged. He could get a nice gleam in his eye and bigger smiles than he could before. He was very much more interested in his mother and father this time, too. In addition, I heard about, and observed a little bit, that Martin could be more purposeful, reaching for things, patting his father on the face, and, at home, even getting some beginning back-and-forth going, for example, taking noodles from his father's mouth and then doing that over and over again.

Martin was not yet able to sustain long back-and-forth interactions. We could also see that he was better able to coordinate what he saw and did with his motor movements. He was able to coordinate those two with listening to sounds as well. Martin was better able to coordinate his senses toward purposeful action, and we would expect to greater improvement in this area as well.

Contributing to Martin's challenges were motor delays. He was able to sit up with a little bit of help and then sustain the sitting, but he was not yet able to crawl or walk, although he could use a walker. He was not yet able to make sounds, other than sounds of discomfort, but could responding receptively to words like "up," in this case, by putting his hands up. He was also able to show preferences and choices, especially by looking.

|           | <b>Questionnaire</b> | <b>Clinical</b> |
|-----------|----------------------|-----------------|
| <b>1.</b> | <b>4</b>             | 3               |
| <b>2.</b> | <b>4</b>             | 4               |
| <b>3.</b> | <b>4</b>             | 3               |
| <b>4.</b> | <b>2</b>             | 2               |
| <b>5.</b> | <b>1</b>             | 1               |
| <b>6.</b> | <b>1</b>             | 1               |

## Preliminary Study of the Relationship Between the FEDQ and Video Taped Observations of Child-Caregiver Interactions

In order to see if the questions we formulated were obtaining information on the child's functional developmental capacities (in particular, if each question or group of questions was yielding relevant information), we administered the questionnaire and videotaped and analyzed the caregiver/child interactions for 39 children and caregivers. In order to analyze the videotapes, we used the clinical descriptions contained in Table 2 (the degrees of mastery possible for each stage) and used a seven point rating scale of the degree of mastery obtained as reported by parents.

We had two raters score the first group of eight videotapes (the originator of the Functional Emotional Developmental Model and the FEAS and a recently trained student) (See Table 3). The second group of 31 cases are clinically rated only by the originator of the Functional Emotional Developmental Model and the FEAS. The cases were also divided into three groups: (1) children with autistic spectrum (PDD), disorders (P); (2) children with regulatory problems (R); and (3) children who were highly competent and viewed as functioning optimally by their parents (O) (See Table 4).

### Reliability Study on the First Eight Cases

Below we present the FEDQ and clinical ratings of two raters on the first eight cases.

**Table 3: Clinical Ratings by Two Raters on the First Eight Cases As Well As the FEDQ Ratings**

| Case       | #  | Questionnaire Results | Clinical Ratings |         |
|------------|----|-----------------------|------------------|---------|
|            |    |                       | Rater 1          | Rater 2 |
| Case 1 (P) | 1. | 4                     | 4                | 4       |
|            | 2. | 5                     | 5                | 5       |
|            | 3. | 5                     | 5                | 5       |
|            | 4. | 4                     | 3                | 4       |
|            | 5. | 5                     | 4                | 4       |
|            | 6. | 5                     | 3                | 3       |
| Case 2 (P) | 1. | 4                     | 4                | 3       |
|            | 2. | 3                     | 3                | 3       |
|            | 3. | 2                     | 2                | 2       |
|            | 4. | 2                     | 1.5              | 2       |
|            | 5. | 1                     | 1                | 1       |
|            | 6. | 1                     | 1                | 1       |
| Case 3 (P) | 1. | 4                     | 4                | 4.5     |
|            | 2. | 4                     | 4                | 4       |
|            | 3. | 4                     | 4                | 4       |
|            | 4. | 3.5                   | 3                | 3       |
|            | 5. | 2                     | 2                | 2       |
|            | 6. | 1                     | 1                | 1       |

**Table 3:** (Continued)

|                   |           |            |     |     |
|-------------------|-----------|------------|-----|-----|
| <b>Case 4 (P)</b> | <b>1.</b> | <b>4</b>   | 4   | 4   |
|                   | <b>2.</b> | <b>5</b>   | 5   | 5   |
|                   | <b>3.</b> | <b>5</b>   | 5   | 5   |
|                   | <b>4.</b> | <b>5</b>   | 4   | 4   |
|                   | <b>5.</b> | <b>4</b>   | 5   | 4   |
|                   | <b>6.</b> | <b>3</b>   | 3   | 3.5 |
| <b>Case 5 (R)</b> | <b>1.</b> | <b>5</b>   | 5   | 5   |
|                   | <b>2.</b> | <b>5</b>   | 5   | 5   |
|                   | <b>3.</b> | <b>5</b>   | 5   | 5   |
|                   | <b>4.</b> | <b>5</b>   | 4   | 4.5 |
|                   | <b>5.</b> | <b>3</b>   | 3   | 3.5 |
|                   | <b>6.</b> | <b>2</b>   | 2.5 | 2   |
| <b>Case 6 (R)</b> | <b>1.</b> | <b>7</b>   | 5   | 5   |
|                   | <b>2.</b> | <b>4</b>   | 4   | 5   |
|                   | <b>3.</b> | <b>7</b>   | 6   | 6   |
|                   | <b>4.</b> | <b>4</b>   | 4   | 5   |
|                   | <b>5.</b> | <b>4</b>   | 3   | 4   |
|                   | <b>6.</b> | <b>6</b>   | 3   | 4   |
| <b>Case 7 (R)</b> | <b>1.</b> | <b>4</b>   | 5   | 5   |
|                   | <b>2.</b> | <b>4</b>   | 5   | 5   |
|                   | <b>3.</b> | <b>5</b>   | 5   | 5   |
|                   | <b>4.</b> | <b>7</b>   | 4   | 4   |
|                   | <b>5.</b> | <b>3.5</b> | 4   | 4   |
|                   | <b>6.</b> | <b>4</b>   | 3   | 3   |
| <b>Case 8 (R)</b> | <b>1.</b> | <b>5</b>   | 7   | 6   |
|                   | <b>2.</b> | <b>5</b>   | 6   | 6   |
|                   | <b>3.</b> | <b>7</b>   | 6   | 6   |
|                   | <b>4.</b> | <b>7</b>   | 7   | 6   |
|                   | <b>5.</b> | <b>6</b>   | 5   | 5   |
|                   | <b>6.</b> | <b>5</b>   | 5   | 5   |

As can be seen, the clinical ratings of both raters are quite similar.

### **Correspondence of Clinical and FEDQ Ratings (for Thirty-Nine Cases) and a Comparison of Three Groups (A Group with Pervasive Developmental Disorders, A Group with Regulatory Problems, and a Group Functioning Optimally)**

This section presents FEDQ and clinical ratings for the remaining 31 cases and the comparison of the clinical and FEDQ ratings for all 39 cases. We also present the patterns we observed in three groups of children—a group with autistic spectrum disorders (PDD), a group with regulatory problems, including attention, behavioral regulation, sensory integration, sensory processing, and motor planning challenges, and an optimally functioning group that had no known clinical challenges and who were doing very well in school, with friends, and with family.

We would predict that the group with autistic spectrum (PDD patterns) would have significant impairments in the early functional emotional developmental capacities, such as shared attention, engagement, and two-way, affective signaling with gestures. They would also have very limited advanced capacities. The group with regulatory problems would be expected to have moderately strong early functional emotional developmental capacities for engagement and two-way gestural communication, and the ability to create ideas but varying degrees of compromise in higher-level capacities, depending on their motor and sensory processing profiles. Overall, they would evidence a different profile and show higher-level capacities than the group with autistic spectrum disorders. The optimal group would be expected to have optimal or close to optimal functional emotional developmental capacities at both the early and advanced levels. Note that the first eight cases used to see if two clinical raters could agree in their clinical ratings are also labeled in terms of the three categories described above (so that they can be included in the comparisons of both the relationship between the FEDQ and the clinical ratings and the differences between the three groups).

Table 4

| Children with PDD                          | #         | FEDQ     | Clinical | Children with PDD                               | #         | FEDQ       | Clinical |
|--|-----------|----------|----------|---|-----------|------------|----------|
| <b>Case 1P</b>                             | <b>1.</b> | <b>4</b> | 3        | <b>Case 6P</b>                                  | <b>1.</b> | <b>3</b>   | 3        |
| 16 mo. old boy                             | <b>2.</b> | <b>4</b> | 4        | 5 year old boy                                  | <b>2.</b> | <b>3.5</b> | 3.5      |
| (Case 14 in narrative)                     | <b>3.</b> | <b>4</b> | 3        | (Case 6 in narrative)                           | <b>3.</b> | <b>4</b>   | 3.5      |
|  | <b>4.</b> | <b>2</b> | 2        |   | <b>4.</b> | <b>3.5</b> | 3.5      |
|  | <b>5.</b> | <b>1</b> | 1        |   | <b>5.</b> | <b>3.5</b> | 3.5      |
|  | <b>6.</b> | <b>1</b> | 1        |   | <b>6.</b> | <b>1</b>   | 1.5      |
| <b>Case 2P</b>                             | <b>1.</b> | <b>3</b> | 3        | <b>Case 7P</b>                                  | <b>1.</b> | <b>4</b>   | 3.5      |
| 2 <sup>2</sup> / <sub>3</sub> year old boy | <b>2.</b> | <b>3</b> | 3        | 8 year old boy                                  | <b>2.</b> | <b>5</b>   | 4        |
| (Case 3 in narrative)                      | <b>3.</b> | <b>3</b> | 3        |   | <b>3.</b> | <b>4</b>   | 4        |
|  | <b>4.</b> | <b>2</b> | 2        |   | <b>4.</b> | <b>4</b>   | 3        |
|  | <b>5.</b> | <b>3</b> | 2.5      |   | <b>5.</b> | <b>2</b>   | 2        |
|  | <b>6.</b> | <b>1</b> | 1        |   | <b>6.</b> | <b>2</b>   | 2        |
| <b>Case 3P</b>                             | <b>1.</b> | <b>3</b> | 3        | <b>Case 8P</b>                                  | <b>1.</b> | <b>3.5</b> | 3.5      |
| Almost 4 year old girl                     | <b>2.</b> | <b>3</b> | 3        | 8 <sup>1</sup> / <sub>2</sub> year old boy      | <b>2.</b> | <b>5</b>   | 5        |
| (Case 2 in narrative)                      | <b>3.</b> | <b>3</b> | 3        |   | <b>3.</b> | <b>5</b>   | 4.5      |
|  | <b>4.</b> | <b>3</b> | 2.5      |   | <b>4.</b> | <b>5</b>   | 4.5      |
|  | <b>5.</b> | <b>3</b> | 2.5      |   | <b>5.</b> | <b>3.5</b> | 3.5      |
|  | <b>6.</b> | <b>2</b> | 2        |   | <b>6.</b> | <b>4.5</b> | 3.5      |
| <b>Case 4P</b>                             | <b>1.</b> | <b>2</b> | 2        | <b>Case 9P</b>                                  | <b>1.</b> | <b>3</b>   | 3.5      |
| 4 <sup>1</sup> / <sub>2</sub> year old boy | <b>2.</b> | <b>3</b> | 3        | 8 <sup>1</sup> / <sub>2</sub> to 9 year old boy | <b>2.</b> | <b>6</b>   | 5        |
| (Case 8 in narrative)                      | <b>3.</b> | <b>3</b> | 2.5      | (Case 1 in narrative)                           | <b>3.</b> | <b>4</b>   | 4        |
|  | <b>4.</b> | <b>2</b> | 2        |   | <b>4.</b> | <b>3</b>   | 3        |
|  | <b>5.</b> | <b>2</b> | 2        |   | <b>5.</b> | <b>3</b>   | 3        |
|  | <b>6.</b> | <b>1</b> | 1        |   | <b>6.</b> | <b>1</b>   | 1        |
| <b>Case 5P</b>                             | <b>1.</b> | <b>5</b> | 5.5      | <b>Case 10P</b>                                 | <b>1.</b> | <b>3</b>   | 3        |
| 4 <sup>4</sup> / <sub>5</sub> year old boy | <b>2.</b> | <b>7</b> | 7        | 10 year old boy                                 | <b>2.</b> | <b>7</b>   | 7        |
|  | <b>3.</b> | <b>6</b> | 6        |   | <b>3.</b> | <b>3</b>   | 3        |
|  | <b>4.</b> | <b>4</b> | 4        |   | <b>4.</b> | <b>3</b>   | 3        |

|             |     |             |   |
|-------------|-----|-------------|---|
| <b>5. 6</b> | 6   | <b>5. 3</b> | 3 |
| <b>6. 5</b> | 5.5 | <b>6. 3</b> | 3 |
| <b>7. 4</b> | 4   | <b>7. 1</b> | 1 |
| <b>8. 1</b> | 1   |             |   |
| <b>9. 1</b> | 1   |             |   |

| <b>Children with<br/>Regulatory<br/>Disorder</b> |               |                 | <b>Children with<br/>Regulatory<br/>Disorder</b> |               |                 |
|--|---------------|-----------------|--|---------------|-----------------|
|  | <b># FEDQ</b> | <b>Clinical</b> |  | <b># FEDQ</b> | <b>Clinical</b> |
| <b>Case 1R</b>                                   | <b>1. 5</b>   | 5               | <b>Case 7R</b>                                   | <b>1. 5</b>   | 5               |
| 3 year old boy                                   | <b>2. 5</b>   | 6               | 8 year old boy                                   | <b>2. 6</b>   | 6               |
| (Case 4 in narrative)                            | <b>3. 5</b>   | 5.5             |  | <b>3. 7</b>   | 7               |
|  | <b>4. 5</b>   | 5               |  | <b>4. 5</b>   | 5               |
|  | <b>5. 5</b>   | 5               |  | <b>5. 5</b>   | 5               |
|  | <b>6. 5</b>   | 5               |  | <b>6. 3</b>   | 3               |
|  |               |                 |  | <b>7. 1</b>   | 1               |
|  |               |                 |  | <b>8. 1</b>   | 1               |
| <b>Case 2R</b>                                   | <b>1. 7</b>   | 7               | <b>Case 8R</b>                                   | <b>1. 7</b>   | 6               |
| 6 year old boy                                   | <b>2. 7</b>   | 8               | 9 year old girl                                  | <b>2. 7</b>   | 7               |
| (Case 5 in narrative)                            | <b>3. 6</b>   | 6               |  | <b>3. 7</b>   | 6               |
|  | <b>4. 6</b>   | 6               |  | <b>4. 6</b>   | 6               |
|  | <b>5. 6</b>   | 6               |  | <b>5. 5.5</b> | 5.5             |
|  | <b>6. 6</b>   | 6               |  | <b>6. 5.5</b> | 5.5             |
|  | <b>7. 3.5</b> | 4               |  | <b>7. 3</b>   | 3               |
|  | <b>8. 4</b>   | 4               |  | <b>8. 3</b>   | 3               |
| <b>Case 3R</b>                                   | <b>1. 5</b>   | 5.5             | <b>Case 9R</b>                                   | <b>1. 7</b>   | 7               |
| 6 year old boy                                   | <b>2. 6</b>   | 5.5             | 10 year old boy                                  | <b>2. 5</b>   | 7               |
| (Case 11 in narrative)                           | <b>3. 5.5</b> | 5.5             | Rater 1(J)                                       | <b>3. 7</b>   | 7               |
|  | <b>4. 5.5</b> | 5.5             |  | <b>4. 7</b>   | 6 to 7          |
|  | <b>5. 5</b>   | 5               |  | <b>5. 7</b>   | 6               |
|  | <b>6. 5</b>   | 5               |  | <b>6. 3</b>   | 4               |
|  | <b>7. 3.5</b> | 3               |  |               |                 |
| <b>Case 4R</b>                                   | <b>1. 5</b>   | 5               | <b>Case 10R</b>                                  | <b>1. 6</b>   | 6               |
| 7 year old boy                                   | <b>2. 6</b>   | 6               | 11 year old boy                                  | <b>2. 7</b>   | 7               |
| (Case 7 in narrative)                            | <b>3. 6</b>   | 6               |  | <b>3. 7</b>   | 7               |
|  | <b>4. 6</b>   | 6               |  | <b>4. 6</b>   | 6               |
|  | <b>5. 6</b>   | 6               |  | <b>5. 7</b>   | 7               |
|  | <b>6. 5</b>   | 6               |  | <b>6. 6</b>   | 6               |
|  | <b>7. 4</b>   | 3               |  | <b>7. 4</b>   | 4               |
|  |               |                 |  | <b>8. 4</b>   | 4               |
|  |               |                 |  | <b>9. 1</b>   | 1               |
| <b>Case 5R</b>                                   | <b>1. 5</b>   | 5               | <b>Case 11R</b>                                  | <b>1. 6</b>   | 5.5             |
| 7 1/2 year old boy                               | <b>2. 7</b>   | 6               | 13 year old boy                                  | <b>2. 6</b>   | 6               |
| (Case 10 in narrative)                           | <b>3. 6</b>   | 6               |  | <b>3. 6</b>   | 5.5             |
|  | <b>4. 5.5</b> | 5.5             |  | <b>4. 5</b>   | 5               |
|  | <b>5. 5.5</b> | 5.5             |  | <b>5. 5</b>   | 5.5             |
|  | <b>6. 5</b>   | 5               |  | <b>6. 5</b>   | 5               |
|  | <b>7. 3</b>   | 4               |  | <b>7. 4</b>   | 4               |
|  | <b>8. 3</b>   | 3               |  | <b>8. 4</b>   | 4               |
|  |               |                 |  | <b>9. 1</b>   | 1               |

|                                       |    |   |                     |                                 |    |   |   |
|---------------------------------------|----|---|---------------------|---------------------------------|----|---|---|
| <b>Case 6R</b><br>7 1/2 year old girl | 1. | 7 | 7                   | <b>Case 12R</b><br>(Rater 1[I]) | 1. | 7 | 7 |
|                                       | 2. | 7 | 7                   |                                 | 2. | 4 | 7 |
|                                       | 3. | 7 | 7                   |                                 | 3. | 7 | 6 |
|                                       | 4. | 7 | 7                   |                                 | 4. | 7 | 6 |
|                                       | 5. | 7 | 7                   |                                 | 5. | 5 | 5 |
|                                       | 6. | 5 | 5                   |                                 | 6. | 5 | 5 |
|                                       | 7. | 5 | 5                   |                                 |    |   |   |
|                                       | 8. | 5 | 5                   |                                 |    |   |   |
|                                       | 9. | - | 1 - not<br>aged yet |                                 |    |   |   |

| Children with<br>Optimal<br>Functioning |    |      | Children with<br>Optimal<br>Functioning |                                      |    |      |          |
|---|----|------|---|--------------------------------------|----|------|----------|
|   | #  | FEDQ | Clinical                                |                                      | #  | FEDQ | Clinical |
| <b>Case 1-O</b><br>8 year old boy       | 1. | 7    | 7                                       | <b>Case 6-O</b><br>19 year old girl  | 1. | 7    | 7        |
|   | 2. | 7    | 7                                       |                                      | 2. | 7    | 7        |
|   | 3. | 7    | 7                                       |                                      | 3. | 7    | 7        |
|   | 4. | 7    | 7                                       |                                      | 4. | 7    | 7        |
|   | 5. | 7    | 7                                       |                                      | 5. | 7    | 7        |
|   | 6. | 7    | 7                                       |                                      | 6. | 7    | 7        |
|   | 7. | 7    | 7                                       |                                      | 7. | 7    | 7        |
|   | 8. | 7    | 7                                       |                                      | 8. | 7    | 7        |
|   | 9. | 4    | 4                                       |                                      | 9. | 7    | 7        |
| <b>Case 2-O</b><br>9 year old boy       | 1. | 7    | 7                                       | <b>Case 7-O</b><br>20 year old woman | 1. | 7    | 7        |
|   | 2. | 7    | 7                                       |                                      | 2. | 7    | 7        |
|   | 3. | 7    | 7                                       |                                      | 3. | 7    | 7        |
|   | 4. | 7    | 7                                       |                                      | 4. | 7    | 7        |
|   | 5. | 7    | 7                                       |                                      | 5. | 7    | 7        |
|   | 6. | 7    | 7                                       |                                      | 6. | 7    | 7        |
|   | 7. | 7    | 7                                       |                                      | 7. | 7    | 7        |
|   | 8. | 7    | 7                                       |                                      | 8. | 7    | 7        |
|   | 9. | 4    | 4                                       |                                      | 9. | 7    | 7        |
| <b>Case 3-O</b><br>10 year old          | 1. | 7    | 7                                       | <b>Case 8-O</b><br>21 year old man   | 1. | 7    | 7        |
|   | 2. | 7    | 7                                       |                                      | 2. | 7    | 7        |
|   | 3. | 7    | 7                                       |                                      | 3. | 7    | 7        |
|   | 4. | 7    | 7                                       |                                      | 4. | 7    | 7        |
|   | 5. | 7    | 7                                       |                                      | 5. | 7    | 7        |
|   | 6. | 7    | 7                                       |                                      | 6. | 7    | 7        |
|   | 7. | 7    | 7                                       |                                      | 7. | 7    | 7        |
|   | 8. | 7    | 7                                       |                                      | 8. | 6    | 7        |
|   | 9. | 3    | 3                                       |                                      | 9. | 6    | 6        |
| <b>Case 4-O</b><br>11 year old boy      | 1. | 7    | 7                                       | <b>Case 9-O</b><br>22 year old man   | 1. | 7    | 7        |
|   | 2. | 7    | 7                                       |                                      | 2. | 7    | 7        |
|   | 3. | 7    | 7                                       |                                      | 3. | 7    | 7        |
|   | 4. | 7    | 7                                       |                                      | 4. | 7    | 7        |
|   | 5. | 7    | 7                                       |                                      | 5. | 7    | 7        |
|   | 6. | 7    | 7                                       |                                      | 6. | 7    | 7        |
|   | 7. | 6    | 7                                       |                                      | 7. | 7    | 7        |
|   | 8. | 6    | 6                                       |                                      | 8. | 7    | 6        |
|   | 9. | 6    | 6                                       |                                      | 9. | 7    | 6        |

|                 |             |   |
|-----------------|-------------|---|
| <b>Case 5-O</b> | <b>1. 7</b> | 7 |
| 14 year old boy | <b>2. 7</b> | 7 |
|                 | <b>3. 7</b> | 7 |
|                 | <b>4. 7</b> | 7 |
|                 | <b>5. 7</b> | 7 |
|                 | <b>6. 7</b> | 7 |
|                 | <b>7. 7</b> | 7 |
|                 | <b>8. 6</b> | 6 |
|                 | <b>9. 6</b> | 6 |

As can be seen, at a descriptive level there appears to be encouraging similarities between FEDQ ratings and clinical ratings. Also, FEDQ patterns appear to describe different functional emotional developmental patterns in the manner expected for the three groups. This provides preliminary support to further explore and study the usefulness of the FEDQ.

### ***Discussion***

It's important to emphasize that this is a preliminary report presenting a series of questions that attempt to profile complex psychological phenomena. The goal of this report is to provide the reader with the questions and a preliminary picture of their potential to profile the functional emotional developmental capacities. Further studies will need to include systematic reliability and validity studies, as well as studies on the properties of the questionnaire.

In addition, it should be pointed out that future studies will need to look at a larger number of children to observe if the FEDQ can discriminate among children who evidence similar profiles. For example, how well will it discriminate among children with ASD who have challenges at the most basic levels of their functional emotional developmental capacities.

It should also be pointed out that the group of children with optimal functioning in this report were relatively older than the children with ASD and regulatory disorders. This occurred as a by product of children and families that were available to participate in using the questionnaire during the time these observations were being made. Future studies will need to include a group of children with optimal functioning who are matched for age and other relevant characteristics with the clinical groups. In using the FEDQ with younger children with optimal functioning we have observed that their FEDQ profiles tend to reflect relatively competent functioning in all the functional emotional developmental capacities up to the highest levels that would be expected for a child of their age.

### **Conclusion**

Clinical evaluation must include many types of information such as direct clinical observation, review of problems and current functioning, a detailed develop-

mental history, observations of family patterns, and interactions and relevant psychological, developmental and/or biomedical assessments. There are, however, many ways to obtain relevant clinically meaningful information. This article is a preliminary report presenting a new questionnaire to obtain information on an individual's functional emotional developmental capacities at each stage during childhood and early adolescence, as well as in later adolescence and adulthood when developmental functioning does not extend beyond an early adolescent level. It complements and extends the FEAS and the FEAS Growth Chart and Questionnaire. This preliminary report is intended to encourage colleagues to explore the clinical usefulness of the FEDQ and conduct additional clinical applications, as well as reliability and validity studies.

## APPENDIX 1

# The Functional Emotional Developmental Questionnaire for Childhood

**Jacob Greenspan and Stanley I. Greenspan, M.D.**

Name: \_\_\_\_\_ Age: \_\_\_\_\_

The following questions about emotional and intellectual development are evaluated on a seven-point scale. The numbers with no answer next to them indicate choices that fall in between the adjacent answers. Please complete the questions with current information about your child. Please circle the number that most closely applies to your child under each question. Please note that there is an accompanying motor and sensory processing questionnaire that should also be filled out.

- 1a. Can your child be calm, focus, and perform routine tasks at home or at school in an age-appropriate manner when doing something he wants to do (e.g., a baby focusing on Mom's moving face; a school-aged child focusing on playing a game of checkers with you)?

1 – None of the time

2

3 – Rarely

4

5 – Some of the time

6

7 – Most of the time

- 1b. Can your child be calm and focused and perform routine tasks at home or at school in an age-appropriate manner when doing something someone else wants him to do?

1 – None of the time

2

3 – Rarely

4

- 5 – Some of the time  
6  
7 – Most of the time
- 2a. When your child is upset, overwhelmed, or in any type of discomfort does he or she...
- 1 – Withdraw or indiscriminately seek comfort with whoever is closest.  
2  
3 – Look to you for comfort, but is superficial and need oriented.  
4  
5 – Look to you, but if very overwhelmed sometimes shuts down and withdraws.  
6  
7 – Look to you always for comfort.
- 2b. When typically interacting with your child, is he or she...
- 1 – Disengaged and cold.  
2  
3 – Only warm to you when they want something in return.  
4  
5 – Sometimes warm and caring, but are easily distracted from the interacting.  
6  
7 – Mostly or always warm and caring.
3. When you are closely interacting and playing with your child and you make an emotional gesture, i.e. smile or funny face, does he or she...
- 1 – Look disinterested and unresponsive.  
2 – Only interact if you really push and repeatedly try for a response.  
3  
4 – Smile back or respond, but sometimes seem confused and do nothing.  
5 – Smile back and clearly understand your expressions, but with only a limited number of emotional gestures.  
6  
7 – Smile back and clearly understand your expressions with a wide range of emotional gestures.
- 4a. When you and your child are interacting or playing, your child...
- 1 – Can not sustain a back and forth interaction.  
2  
3 – Can only briefly sustain a back and forth interaction, i.e. 20-30 seconds.  
4  
5 – Sometimes can sustain a long back and forth interaction, i.e. 5-10 minutes of either gesturing, playing, or talking with you.

6

7 – Most of the time can sustain a long back and forth interaction.

4b. In a situation where your child needs you to do something for him or her, can use words, gestures, or a combination of the two...

1 – Only very rarely or not at all and, therefore, is not able to let you know what he or she wants.

2

3 – Only sometimes to let you know what he or she wants, but often gets frustrated and give up.

4

5 – And is persistent in letting you know what he or she wants with the same or very similar gestures or verbal directions.

6

7 – And is persistent with letting you know what he or she wants, but can modify and change the directions until you understand. (i.e. can keep showing you in different ways what is wanted)

5a. When your child is frustrated or experiencing some emotion and you ask how he or she feels, the child...

1 – Does not respond and may get confused.

2

3 – Is unable to use words to tell you and instead acts it out by hitting, clinging, or getting excited.

4

5 – Explains how she or he feels for a few feelings (e.g., happy or mad), but can't describe other feelings or use words when emotions are intense.

6

7 – Clearly tells you that he or she is happy, mad, sad, etc., most of the time, even if the feelings are intense.

5b. When playing with or without toys your child is

1 – Unable to develop even basic pretend play with concrete actions (e.g., moving the truck to the house).

2

3 – Able to develop a few elements of a story, but without elaboration, motivations, or feelings (e.g., man put on truck).

4

5 – Create a pretend story with motives and emotions some of the time.

6

7 – Create a story line with motives and emotions most of the time.

6. When your child is feeling certain emotions toward you, he or she is...
- 1 – Unable to tell you why they feel how they do.
  - 2
  - 3 – Can partially tell you how they feel, but thinks that it is the end of the world.
  - 4 – Can tell you how they feel partially, but the explanation wanders and is hard to understand - you can get the gist of their explanation.
  - 5 – Can give you a clear reason for some feelings like happiness, but not others like anger or frustration.
  - 6 – Can give you a clear reason for why they feel a certain way
  - 7 – Can give you a clear reason for why they feel a certain way, even under extreme emotions.

Only answer this question if your answer to question #6 is 5. or higher.

7. Does your child understand that there may be multiple events or reasons causing someone to behave in a certain way? For example, they understand a situation where a friend might be upset with their family life or school and is taking out their aggression on them. Rather than assuming that their friend does not like them, they consider these other possibilities.
- 1 – They always personalize the situation in an extreme way, e.g. she or he hates me.
  - 2
  - 3 – With guidance (e.g. someone helping them think about the multiple reasons for the other persons actions) they are able to consider more than one reason for the other person's actions some of the time.
  - 4
  - 5 – On their own, they are able to consider multiple reasons for other people's actions some of the time.
  - 6
  - 7 – They are able to consider multiple reasons for other people's actions most of the time.

Only answer this question if your answer to question #7 is 5 or higher.

8. Is your child able to distinguish the varying degrees of different feelings for one situation? For example, if participating in a new activity (soccer game, piano recital) they can understand and express that they feel excited to be doing a new thing and a little afraid of not performing well at the same time.
- 1 – Is not yet able to distinguish varying degrees of different feelings for one situation.
  - 2
  - 3 – With guidance (e.g. someone helping them think about the varying degrees of different feelings) they are able to understand and express varying degrees of feelings some of the time.

4

5 – On their own, they are able to express varying degrees of feelings for a situation some of the time.

6

7 – They are able to express varying degrees of feelings for a situation most of the time.

Only answer this question if your answer to question #8 is 5 or higher.

9. Does your child know him or herself well enough to be able to judge how they are feeling or responding to a given situation. For example, they can make judgments such as, "I feel angrier than I should".

1 – They are unable to judge how they are feeling or responding to a given situation.

2

3 – With guidance they are able to judge how they are feeling some of the time.

4

5 – On their own, they are able to judge how they are feeling and responding some of the time on their own.

6

7 – They are able to judge how they are feeling and responding most of the time.

For middle and late adolescence, young adulthood, adulthood, middle age, and the aging process, the ability to think off of an internal sense of self and internal standards broadens to include the new experiences and challenges of these stages of life. For example:

**Adolescence:** includes sexuality, romance, educational and occupational goals, and closer and more intimate peer relationships, venturing out into the community and many new activities.

**Young Adulthood:** includes ability to function independently from, yet remain close to and internalize many of the positive features of one's nuclear family; capacity for sustained intimacy (serious long-term relationships); a capacity to plan and carry out education and career goals.

**Adulthood, Middle Age, and the Aging Process:** includes the capacity to nurture and empathize with one's spouse and children without over identifying with them; the ability to broaden one's nurturing and empathetic capacities beyond one's family into the larger community; the ability to experience and reflect on new feelings of intimacy, pride, competition, disappointment, and loss associated with the family, career, and intra-personal changes of mid-life and the aging process.

The developmental questionnaire for these stages will be presented in a future article.

## **Appendix 1A**

### **Sensory and Motor Processing Capacities That Influence Functional Emotional Capacities**

*Next, fill out the Sensory and Motor Processing questionnaire. These are processing capacities that influence functional emotional capacities. Please note that the standard for all these items is age-appropriate functioning. If the category itself is above age-level expected for the child, please ignore that category and go to the next one. For example, sequencing ideas would be above the age-expectations for a 1 year old child, but not for a 4 year-old child.*

- a. When hearing loud, low-pitched (e.g., motorized sounds) or high-pitched (e.g., violins, piccolos) sounds or in a noisy environment (e.g., shopping mall, airport, or busy classroom) does the sound seem to...
- 1 – Overwhelm and cause your child to withdraw, get upset, or become aggressive.
  - 2
  - 3 – Clearly bother your child, but can be dealt with for a short period of time.
  - 4
  - 5 – Not bother your child, unless there is a huge amount of it or not enough of it.
  - 6
  - 7 – Not bother your child at all
- a1. Do you feel that your child craves and seeks out the type of sounds described above
- 1 – Most of the time
  - 2
  - 3 – Some of the time
  - 4
  - 5 – Rarely
  - 6
  - 7 – None of the time
- b. When in a visually stimulating environment (e.g., bright lights, lots of colors, lots of people) do the sights seem to...
- 1 – Overwhelm and cause your child to withdraw, get upset, or become aggressive.
  - 2
  - 3 – Clearly bother your child, but can be dealt with for a short period of time.
  - 4
  - 5 – Not bother your child, unless there is a huge amount of it or not enough of it.
  - 6
  - 7 – Not bother your child at all

b1. Do you feel that your child craves and seeks out the type of sights described above

1 – Most of the time

2

3 – Some of the time

4

5 – Rarely

6

7 – None of the time

c. When hugging or cuddling with your child, or even when wearing certain clothes does the sensation of touch seem to...

1 – Overwhelm and cause your child to withdraw or become aggressive.

2

3 – Clearly bother your child, but can be dealt with for a short period of time.

4

5 – Not bother your child, unless there is a huge amount of it or not enough of it.

6

7 – Not bother your child at all

c1. Do you feel that your child craves and seeks out the type of touch described above...

1 – Most of the time

2

3 – Some of the time

4

5 – Rarely

6

7 – None of the time

d. Is your child very sensitive to pain so that any scrape or bang tends to be very uncomfortable and even a little scary?

1 – None of the time

2

3 – Rarely

4

5 – Some of the time

6

7 – Most of the time

- e. When in an environment with odors or smells or where, for other reasons, the sense of smell is stimulated (e.g., strong perfumes or food odors), does the smell seem to
- 1 – Overwhelm and cause your child to withdraw, get upset, or become aggressive.
  - 2
  - 3 – Clearly bother your child, but can be dealt with for a short period of time.
  - 4
  - 5 – Not bother your child, unless there is a huge amount of it or not enough of it.
  - 6
  - 7 – Not bother your child at all
- e1. Do you feel that your child craves and seeks out the type of smells described above
- 1 – Most of the time
  - 2
  - 3 – Some of the time
  - 4
  - 5 – Rarely
  - 6
  - 7 – None of the time
- f. When exposed to strong or new tastes (e.g., new foods), does the taste seem to
- 1 – Overwhelm and cause your child to withdraw, get upset, or become aggressive.
  - 2
  - 3 – Clearly bother your child, but can be dealt with for a short period of time.
  - 4
  - 5 – Not bother your child, unless there is a huge amount of it or not enough of it.
  - 6
  - 7 – Not bother your child at all
- f1. Do you feel that your child craves and seeks out the types of tastes described above
- 1 – Most of the time
  - 2
  - 3 – Some of the time
  - 4
  - 5 – Rarely
  - 6
  - 7 – None of the time

- g. When your child is in a situation where there is constant motion, i.e. merry-go-round or swing set, does the motion seem to...
- 1 – Overwhelm and cause your child to withdraw or become aggressive.
  - 2
  - 3 – Clearly bother your child, but can be dealt with for a short period of time.
  - 4
  - 5 – Only bothers your child some of the time.
  - 6
  - 7 – Your child is comfortable with movement and motion unless it's something extreme and new
- g1. Do you feel that your child craves and seeks out the type of movement and motion described above...
- 1 – Most of the time
  - 2
  - 3 – Some of the time
  - 4
  - 5 – Rarely
  - 6
  - 7 – None of the time
- h. Can your child carry out a complex set of actions using gross motor activities in an age-appropriate manner, for example, learning a new dance step or learning how to play a new sport and/or negotiating his/her way through an obstacle course?
- 1 – None of the time
  - 2
  - 3 – Rarely
  - 4
  - 5 – Some of the time
  - 6
  - 7 – Most of the time
- i. Is your child able to perform fine motor tasks in an age-appropriate manner (e.g., relatively good at copying shapes, penmanship, and/or being able to draw pictures with many elements to them relatively quickly)?
- 1 – None of the time
  - 2
  - 3 – Rarely
  - 4
  - 5 – Some of the time
  - 6
  - 7 – Most of the time

- j. Is your child relatively strong for his age in sequencing ideas, as in spontaneously arguing a point of view logically and cohesively and/or constructing an essay where one point logically follows another point (instead, for example, tending to jump around from one subject to another—intuitively and creatively, perhaps—but with more difficulty keeping arguments tightly sequenced)?

1 – None of the time

2

3 – Rarely

4

5 – Some of the time

6

7 – Most of the time

- k. Is your child able to follow multi-step verbal directions easily and effortlessly for his/her age—compared to other individuals in that age range (rather than having trouble when a teacher or instructor asks your child to do three or four things in a row)?

1 – None of the time

2

3 – Rarely

4

5 – Some of the time

6

7 – Most of the time

- l. Does your child have a relatively easy time, for his or her age, when hearing a lecture or story in seeing the big picture—understanding the main point and how other points relate to the main point (rather than getting fascinated, perhaps, with some of the specifics and having a hard time understanding the overall point of view of the discussion)?

1 – None of the time

2

3 – Rarely

4

5 – Some of the time

6

7 – Most of the time

- m. Does your child tend to have a wide range of ideas appropriate for his or her age about any subject and be interested in a wide range of subjects? In other words, could your child go on and on and on, free-associating about almost any subject under the sun and/or have a rich and vivid imagination (instead of finding it hard to talk for more than a minute or two without having first studied the subject or

having a more focused imagination, preferring the real world to the imaginative one)?

1 – None of the time

2

3 – Rarely

4

5 – Some of the time

6

7 – Most of the time

- n. Can your child easily “picture” the face of a family member clearly and vividly in his or her mind (instead of thinking about that person’s attributes in words)?

1 – None of the time

2

3 – Rarely

4

5 – Some of the time

6

7 – Most of the time

- o. Can your child systematically search for lost or hidden objects and often find what’s missing and/or does your child have a hard time with a sense of direction?

1 – None of the time

2

3 – Rarely

4

5 – Some of the time

6

7 – Most of the time

- p. Does your child enjoy and is he or she relatively gifted, for his or her age, at broad, theoretical explorations (i.e., the big picture)?

1 – None of the time

2

3 – Rarely

4

5 – Some of the time

6

7 –Most of the time

q. Does your child prefer and is he or she gifted with the specifics or details of a subject (i.e., very good with facts and specifics, the “trees”)?

1 – None of the time

2

3 – Rarely

4

5 – Some of the time

6

7 – Most of the time

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## BOOK REVIEW:

**Molly Romer Witten, Ph. D.**

### **Neurodevelopmental Disorders: Diagnosis and Treatment**

Randi Jenssen Hagerman Oxford University Press (c) 1999

As professionals, there are few reference-oriented books that we wish ‘wouldn’t end’. For the most part, we plow through professional and ‘trade’ books with duty and discipline. We know that we need the information imparted in printed matter. However, the way scientific writers present this information seldom feels immediately useful, and/or satisfying to read, or even integrative. It is part of our training as professionals to learn to delay gratification in favor of acquiring the indispensable knowledge.

*Neurodevelopmental Disorders: Diagnosis and Treatment* by Randi Jenssen Hagerman, published by Oxford University Press in 1999, transcends our usual acceptance of boring, often fragmented and dense analyses of data. She seems to have taken general principles of the scientific thought process, and organized her data according to that intuitive thought process. She has accumulated disparate and unrelated research and integrated it into an immediately useful and user friendly reference. In doing so, she fills a vacuum with much needed information, in a widely available, reader friendly format. Her book covers nine genetically defined syndromes with documented neurological involvement, with varying amounts of co-occurring developmental delay. The nine syndromes are: fetal alcohol syndrome, fragile X syndrome, Tourette Syndrome, sex chromosome aneuploidy in males, sex chromosome aneuploidy in females, Angelman syndrome and Prader-Willi syndrome, 22q deletion syndromes, Williams syndrome, and Smith-Magenis syndrome.

Her organization of each syndrome follows the same pattern. After a short introduction, she presents genetic, physiological, and behavioral diagnostic features, and behavioral and cognitive features of the developmental course. She briefly discusses associated research (implications and animal studies), if she is aware of any. The end of each chapter focuses on intervention strategies that have been documented to work. She illustrates the factual content with one or more brief case histories, which provide the ‘one picture is worth a thousand words’ integration of the data, and a look at the next steps in further understanding of the condition. Such an organization provides the experienced reader with an easy to follow outline for referencing the

issues when they use the book as a reference source. This organization is suited just as well for pre-degree and young professionals, in that it presents a model for how to think about the 'larger picture' of a neuro-behaviorally defined developmental disorder. Her appendices thoughtfully provide resources for following up on various common features of all or most of the disorders such as the co-occurrence of attention deficit, hyperactivity, learning disorders, and technological supports. *'Neurodevelopmental Disorders'* is clearly written for a professional audience. However, parents who would like know the 'state of the knowledge' regarding their child's genetic disorder will benefit from reading it too. It will take some discipline, but it will be well worth it.

Dr. Hagerman's style is approachable, and her sense of involvement with her patients and their families comes through articulately. In a thoughtful manner, she discusses the facts in a straightforward fashion. The case histories that she presents provide an implicit acknowledgment of the undocumented 'real life' issues each syndrome creates. While this book deserves to be on the reference shelf of every professional who works within the field of developmental disorders, I do wish she had been somewhat more thorough in her coverage of interventions and treatments. While she discusses both medical and educational interventions, she does not include psychological or mental health interventions that might be effective in helping families sustain their care, or provide impetus to the developmental process. The omission of this information sends an unintended (one hopes) message that developmental psychotherapy, including early intervention strategies have nothing to contribute to families coping with these neurodevelopmental conditions. Current clinical practice demands that there be a trans-disciplinary approach to the treatment of neurodevelopmental disorders, integrating medicine, psychology, and education as related disciplines, not isolated from each other. Research findings indicate that effective intervention in one of these areas of practice can vastly affect the prognostic course and treatment in another related area.

Further, these neurodevelopmental syndromes constitute chronic conditions, for both the affected individuals and their families. There is an entire body of literature related to how individuals and families can come to cope successfully with the issues resulting from chronic conditions such as neurodevelopmental disorders. However, the author does not include this information, beyond the nod to educational planning. In the next edition, and we need this book to become a classic that can be updated on a regular basis, it would be terrific to find an exploration of this issue as well as the dual issues of family functioning, and school-family collaboration. So, it does fall to writers, especially those with the clarity and power of synthesis that Dr. Hagerman possesses, to provide the broader scope of integration. No one should hesitate to own this book.

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