

Can Children with Autism Master the Core Deficits and Become Empathetic, Creative, and Reflective?

A Ten to Fifteen Year Follow-Up of a Subgroup of Children with Autism Spectrum Disorders (ASD) Who Received a Comprehensive Developmental, Individual-Difference, Relationship-Based (DIR) Approach *

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Abstract

A follow-up study of 16 children diagnosed with an autistic spectrum disorder (ASD) revealed that with the DIR/Floortime approach, a subgroup of children with ASD can become empathetic, creative, and reflective, with healthy peer relationships and solid academic skills. This suggests that some children with ASD can master the core deficits and reach levels of development formerly thought unattainable with a family-oriented approach that focuses on the building blocks of relating, communicating, and thinking.

Can Children with Autism Master the Core Deficits and Become Empathetic, Creative, and Reflective?

There is mounting evidence that emotional processes, such as engagement, joint attention affective reciprocity, and creative play are associated with healthy social, language, and intellectual functioning (Siller & Sigman, 2002; Mundy, Sigman, & Kasari, 1990; Mundy, 1993; Greenspan, 2004). Therefore, we raise the following question: Can these processes be harnessed in children with autism spectrum disorders (ASD) to enable them to make more progress than formerly thought possible? It has been believed that children with ASD are incapable of higher levels of empathy and creative and reflective thinking, no matter how much progress they make academically or with language.

In this paper, we report on a follow-up study of 16 children and families who engaged in the Developmental, Individual-Difference, Relationship-Based (DIR/Floortime) comprehensive intervention program that focused on the building blocks of relating, communicating, and thinking. The DIR/Floortime assessment and intervention program also addresses the individual variations in sensory processing (auditory and visual-spatial processing), sensory discrimination and modulation (including tactile, sound, vestibular, proprioceptive, olfactory, taste, pain, and sight), and motor planning and sequencing (including muscle tone, and coordination), as well as family interactive patterns (Greenspan & Wieder, 1999; 1998; Interdisciplinary Council on Developmental and Learning Disorders Clinical Practice Guidelines Workgroup, 2000).

In this study, we attempted to answer the question of whether or not a subgroup of children diagnosed with ASD could go beyond expectations for high-functioning ASD and learn to be related, empathetic, creative, and reflective thinkers. This report is not intended to be an outcome study of the DIR/Floortime model, but only to answer the specific question raised above. Observing if a subgroup of children with ASD can achieve levels of functioning formerly thought unattainable is especially significant in light of the different intervention approaches now being offered. Some approaches focus more on surface behavioral changes and academic skills and others, such as the DIR/Floortime model, focus more on the developmental processes leading to relating, communicating, and thinking. Looking at the upper limits attainable by a subgroup of children with a good prognosis, who had access to an optimal developmentally-based program can therefore, shed light on both the mechanisms involved in helping children with ASD grow psychologically and intellectually and the potential of some children in an optimal intervention program.

In an earlier paper reviewing 200 cases of children with ASD followed 2 – 8 years after the start of intervention (Greenspan & Wieder, 1997), we reported that a subgroup we treated did exceptionally well, learning to engage, communicate, and think creatively and reflectively with high levels of emotional understanding and empathy. Although in this chart review (summarized below), 58% showed these optimal patterns, the 200 cases reviewed were not a representative population of children with ASD. Therefore, the true size of the subgroup is not known.

Before we present the current study, it will be useful to briefly present an overview of the earlier review to create the context for the current follow-up. Table 1 summarizes the presenting problems of the children and Table 2 the DIR–Floortime Intervention outcomes.

Table 1 – Chart Review of 200 Cases

Developmental Patterns*	
	Presenting Patterns
Engagement	<ul style="list-style-type: none"> • 5% - no affective engagement • 31% - only intermittent engagement • 40% - intermittent engagement and some reciprocity • 24% - intermittent engagement and reciprocity and islands of symbolic capacity • 100% - lacking long chains of reciprocal interactions
Auditory Processing Problems	<ul style="list-style-type: none"> • 100%
Motor Planning Dysfunction	<ul style="list-style-type: none"> • 100%
Reactivity to Sensation	<ul style="list-style-type: none"> • 39% - Underreactive • 19% - Hyperreactive • 36% - Mixed
*Journal of Developmental and Learning Disorders, 1997	

Table 2

DIR–Floortime Intervention Outcomes	
	<i>All Degrees of Implementation of Recommended Program</i> N=200
Good to Outstanding	58%
Medium	25%
Ongoing Difficulties	17%

In the 1997 study, the authors looked more closely at 20 children in the good to outstanding outcome group in two ways (Greenspan & Wieder, 1997). We used the Functional Emotional Assessment Scale (FEAS, Greenspan, DeGangi, & Wieder, 2001), a reliable and validated instrument which measures emotional, social, and intellectual functioning, to compare these 20 children to an age and socioeconomic status-matched group of peers with no history of developmental challenges, as well as a group of children with ASD who had continuing challenges. We found there were no differences between the DIR/Floortime intervention group and the “typical” peer comparison group in terms of emotional, social, and intellectual functioning, but significant differences with the group that had continuing difficulties. See Table 3. We also assessed the group of twenty with the Vineland Adaptive Behavior Scale which measures three domains. As can be seen in Table 4, the group of twenty scored higher

than age level in all domains, especially in communication and socialization (Sparrow, Balla, & Cicchetti, 1984).

Table 3

FEAS Outcomes			
	<i>N</i>	<i>Mean FEAS</i>	<i>Range</i>
DIR/Floortime Intervention Group	20	74.8	70-76
Normal Comparison Group	14	74.9	65-76
Continuing Significant Difficulties	12	23.7	10-40

Table 4

Vineland Outcomes Sample of Children with Good to Outstanding Outcomes N=15	
Higher than age levels in communication	93%
Higher than age levels in socialization	87%
Higher than age levels in daily living skills	53%

Long-Term Outcomes

In this presentation, we report on a ten to fifteen-year follow-up (since the start of treatment) of 16 of the children for whom we were able to obtain follow-up data. See Table 5.¹ The children were all boys, ranged in age between 12 and 17, with a mean of 13.9 years. This follow-up was exceptional in its comprehensiveness and provides one of the most complete pictures of the development of children diagnosed on the autism spectrum. The follow-up addressed the full range of emotional, social and sensory processing variables in addition to traditional cognitive and academic outcomes. We found this group developed high levels of empathy (very advanced on theory of mind tasks) and were often more empathetic than their peers. Some became very talented in music and writing and some developed into wonderful poets. Most were outstanding students, excelling in many academic areas, while others were average students, while a few struggled academically with learning disabilities because of executive functioning and sequencing problems. As a group, they showed the expected range of mental health problems,

¹ Fourteen of these children were in the validating group identified above (with Vineland) and two more were in the group for whom the FEAS was completed.

often depending upon family circumstances, and a few were anxious or depressed as adolescents. . Importantly, however, they coped with the stresses of puberty, family conflicts (including divorce), parent illness (cancer) and maintained their core gains in relating, communicating, and reflective thinking. Since this was the second follow up of this group, it is also noteworthy that they not only maintained their initial gains {Greenspan & Wieder 1997}, but made further progress and were overall equipped to handle the stressors of adolescence and life events.

Table 5

Follow Up of Long Term Outcomes

Report on cases originally used to validate outcomes with the Vineland and FEAS in our 1997 Chart Review of 200 Cases

- Current Ages – 12 to 17 years
- 16 boys
- First concerns between 12 and 24 months
- All diagnosed with PDD or Autistic Spectrum between 24 and 30 months by others

Excerpts from Interviews with Four Boys in Follow Up Study

Before we describe these children in more detail, let's look at a few excerpts from recent videotaped interviews. Two interviews were conducted by parents in their home and two by interviewers (first author and research assistant).

David, age 12 1/2, eighth grade.

David is a warm, friendly, confident youngster with curly hair, a big metallic smile, and impish gleam in his eyes. He is both amused and awkward in creating the videotaped vignettes of his life but cooperates as the camera follows him. The video starts with David lounging on a sunny deck in the back of his home as he spontaneously reports on all the activities he is enjoying now, exuding considerable self confidence and pausing to directly look at the camera to convey a message of appreciation.

Parent: So, tell us what you are doing these days, David.

David: "Right now I'm playing the sax, the piano, and I've got lots of good friends, and I'm getting really good grades. And I'm also in the jazz band at school and I'm getting ready for my bar mitzvah now and I'm almost ready. Last summer I went to ____ Camp and I had a great time. I took up water skiing. Right now I'm learning to slalom on one ski and I'm just having a great time lately. And I owe it to you."

As the tape continues, we see scenes where David is meeting with his basketball team and playing video games with his friend. Later, we hear him say, "All right, I'll clean up the room, I'll clean up the room, just stop bugging me!" We also see him helping his sister with her homework. The tape is an impressive compilation of different scenes from this child's life, reflecting the range of his self-confident functioning.

Adam, age 14, 9th grade

The second child, Adam, was taped late at night by his mother and was being pushed to do the interview. Adam is seen lying semi-curved up on the couch, eyes half-closed, complaining about doing homework. He drags out each word, giving half-answers, with a "get me" gleam in his eye letting his mother know she will have to work for his answers, yet warm and humorous. Here we will see a young adolescent reflecting off an internal standard as he discovers himself as a person who likes to learn. Although it started with "pulling teeth," as one would expect of an adolescent, and initially he couldn't admit that he liked school, Adam actually went on to talk about how much he liked school and the assignments that interested him. As a younger adolescent he also knows how to goad his mother into saying "no" enjoying how well he can predict her behavior!

Parent: Who forces you to do homework?

Adam: Take a guess.

Parent: Me?

Adam: Take another guess.

Parent: Dad.

Adam: Take another guess.

Parent: Miss _____?

Adam: Well, the whole school.

Parent: So, do you like school?

Adam: It's okay, yeah.

Parent: Are you happy at school?

Adam: Yeah.

Parent: Adam, why are you sitting like that?

Adam: I'm tired.

Parent: Why are you tired?

Adam: *Because I'm sleepy.*
 Parent: *What time did you get up?*
 Adam: *Basically the time I get up every day: 6:45.*
 Parent: *That's so early. So, do you feel tired at school?*
 Adam: *Yeah, I want to fall asleep but I know I can't. And even if I could, I probably couldn't.*
 Parents: *It sounds to me, just hearing this snippet of conversation for the last 15 minutes we've had, that you don't like school. Is that true? It just sounds as if you think school's kind of boring.*
 Adam: *No, I think . . . I like it, it's just I don't really want to say it because I'm tired.*
 Parent: *So, did I get you at a bad moment tonight because you're tired?*
 Adam: *I'm tired and I didn't realize it would take this long.*
 Parent: *Oh, should I get you at quarter of seven in the morning instead?*
 Adam: *Can I watch my big television now?*
 Parent: *No!!!.*

The whole tape is a wonderful, lazy flow of a typical adolescent boy being pushed to do an interview when he'd rather be doing something else.

Sam, age 16, 10th grade

Sam is a tall, handsome disheveled teenager with long dark hair who chats spontaneously and confidently, conveying "I know about life now!" He enjoys his mature status and has an opinion about everything. In the next clip we will see Sam reflect on the elections which just finished.

Interviewer: *Any other topics to explore? You shared a lot of good stuff and your opinions, which is what we wanted to hear, how you feel about things – so what do you think about yesterday's events and the way this election turned out?*
 Sam: *I didn't like how it turned out.*
 Interviewer: *Yeah, yeah.*
 Sam: *I don't know. I saw a really, really dumb commercial. It was about this woman saying she lost her sister or something and she looks at George Bush and George Bush knew about it, and he hugged her, and her saying, you know, Bush is so caring. And, I mean, in public everyone's going to do that for a photo op. I mean, just because Bush hugged a little girl in public doesn't mean you should vote for him just because you think he's compassionate. You know, we attacked Iraq with no good reason. We found Saddam Hussein in a hole. We haven't found the weapons of mass destruction for the simple reason there are none there. And they never really attacked us unless you count the time a long time ago. They had nothing to do with it. They had nothing to do with 9/11.*
 Interviewer: *Have you seen the Michael Moore movie?*
 Sam: *Yes, I have. I liked it.*

Interviewer: Yeah, what'd you think of that?

Sam: He over-exaggerated a few things, but there were a few things I didn't know about. I did not know how many of those . . . “

Sam went on for quite a while and had something to say about everything. He was not only interested in his own life, but was quite a student of the world, politics, and people. It was striking how he was now thinking and empathizing with others, no longer at the center of his own universe. He enjoyed a rich extra-curricular life, had many friends, and excelled at school.

Jack, age 17, high school senior

Another boy, Jack, a tall lanky adolescent, appeared more serious and thoughtful. He was one of our oldest teenagers in the outcome study. He was an outstanding student, continued to enjoy a team sport he had started playing as a kid, and volunteered to help the poor. Jack was a senior in high school applying to colleges and was asked what he might like to study. In this clip he reflects on journalism and an interest he developed during his senior year in high school.

Jack: This (journalism) is my favorite thing to do.

Interviewer: What do you write about?

Jack: A bunch of things – I write for my newspaper, I write about history, I write about theology. My favorite subjects are theology, history, and English. They're analytical subjects.

Interviewer: They sure are. How did you get interested in theology?

Jack: I didn't even know what it was till this year, but I had taken a class this year and it just really interested me – the different views that people have of God. It's very interesting, because there're so many different ways to look at it.

Interviewer: What do you think? What is your view?

Jack: I honestly am not sure. But it's definitely something I want to continue studying.

Interviewer: Why does it interest you?

Jack: Because it's more analyzing. Anything like philosophy and theology you can analyze what life is, what the meaning of life is – it's very interesting to be able to do that!

Jack was intrigued with the meaning of life at this stage as he was about to embark on a life away from home. As a student he had relied upon structure and good grades to define himself. As will be seen when we discuss the academic outcomes, many of the children in the follow-up study not only took regular high-level academic courses in school, but took some Advanced Placement and honors courses as well. These children were capable of multi-causal thinking and were very interested in reflecting on what things meant to them. They saw things in “shades of gray” In other words, they had reflective thinking capacities.

The major findings of this follow-up are illustrated by these four clips showing engaging adolescents who could relate with warmth and empathy, express their opinions, give to others,

and reflect on the world around them as they grew older. They were doing the hard work of adolescence in all respects as they studied hard, played hard, and related to others with openness and confidence they could hold their own. Speaking with them, it was hard to remember that they were all children once diagnosed with ASD between two and four years of age. The intensive DIR based interventions which allowed them to change and develop will be described below. What is noteworthy is that for this subgroup of children the core deficits appear to be reversible. Furthermore, in this follow-up study we saw that even after the intervention was completed, the children in this subgroup continued to hold their gains and continue to develop in a healthy way.

Parents Perspectives

The children in this subgroup are now 12 to 18 years of age. When we reported on their cases in the 1997 study, they were between four and eight years old. Considerable time had passed and we were interested in hearing the parents' perspectives of how their children were functioning at the present time.

Our first query to the parents was open-ended: "Tell us how your child is doing" and these are some of their first words:

"Amazing when I think about who he was."

"A miracle child."

"He's doing great."

"He's happy."

"I'm not parenting a child with special needs, just an adolescent boy."

Other parents reported :

"He is sweet, empathic, accommodating, and earnest"

"So caring and observant, so humorous"

"He is in touch with himself and others"

We were struck by how the parents first described the emotional qualities they valued in their children rather than their academic achievements and the lingering awe they felt that the children they were told were autistic had become such wonderful, well grounded kids. Their comments reflected upon a group of very empathic, compassionate young men who were caring, funny, and observant of others. Some were still working hard, struggling with some academic areas and other challenges, but all had become part of life in all its dimensions.

Information Collected for the Follow-Up Study

We conducted parent interviews and asked parents to complete a functional emotional developmental questionnaire (FEDQ) (Greenspan & Greenspan, 2002) which provided their ratings of various domains described below. We also rated our impressions of the children independently based on the interviews. For some, we used videotapes made by parents or our direct interviews with the children, and with others audiotapes recorded via telephone. These provided the basis for the independent clinician ratings that were conducted separately from the parent ratings which were mailed in. We collected school reports and obtained IQ tests when available. It is interesting to note that very few of the children were tested for IQ. Most parents indicated there was no need to have their children tested. We also administered the Achenbach

Scales (Achenbach, 1991), a child behavior checklist (CBCL) that rates competence and clinical syndromes, to provide an objective assessment. See Table 6.

Table 6

<p style="text-align: center;">Current Study</p> <p style="text-align: center;"><i>Follow up study included:</i></p> <ul style="list-style-type: none">• Parent Interviews and FEDQ Ratings• Clinician FEDL Ratings Independent of Parent Ratings• Child Interviews (videotaped)• School and Cognitive Reports• Child Behavior Check List – Achenbach Scales (CBCL)
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The DIR/Floortime Intervention Program

The DIR/Floortime approach provides a comprehensive framework for understanding and treating children challenged by autism spectrum and related disorders. It focuses on helping children master the building blocks of relating, communicating and thinking, rather than on symptoms alone. As can be seen in the Tables below, all the children received comprehensive intervention programs, including five to thirteen different types of interventions depending on their individual needs. An average of eight specific interventions were implemented between ages two and eight and a half. All the children received DIR/Floortime consultations from one of the authors and all did Floortime at home. Fifty-six percent of children had additional Floortime therapy. The emphasis, however, was on the home program. Seventy-five percent implemented a very serious play date program we recommended – at two, have two play dates a week, at three have three play dates, etc. through kindergarten and then to maintain as many as possible during school years. In addition, all the children received speech and language therapy and many continued these therapies for a few years after preschool. All children received clinic based occupational therapy with sensory integration, in addition to their home program. All also received auditory integration therapy. When asked which interventions were most effective, parents reported that Floortime at home, Floortime therapy with their child and a therapist, and playmates were the most significant interventions.

Other therapies varied quite a bit. Some of these therapies have become more popular now, but were not so at the time (e.g., casein/gluten-free diets). At school age a small number continued Floortime therapy, two started psychotherapy during adolescence, and four children received educational therapy. Several children also received tutoring for specific school subjects when needed.

Table 7

Comprehensive Intervention Profiles	
• Average number of different interventions:	8
• Range of interventions:	5 -13
• Ages:	2 – 8.5 years
• Duration of intensive interventions:	2 - 5 years

Table 8

Comprehensive Intervention Profiles N=16	
DIR Consultation	100%
Floortime at Home	100% ✓
Floortime Therapy	56% ✓
Play Dates	75% ✓
Speech and Language Therapy	100%+
Occupational Therapy	100%+
AIT/Tomatis	100%
Visual Spatial Therapy	19%
Biomedical	38%
Cognitive/Ed Therapy	13%/13%
Nutrition	44%+
Diet	13%/25%
Meds at School Age	25%
Family Therapy at school age	13%
Adolescent Psychotherapy	19%
Other	19%
✓ = Parents report most efficacy; + = also helpful	

Parent Ratings of Functional Emotional Developmental Capacities

We asked the parents to rate their children on items organized around the six core developmental capacities and three higher order abstract capacities using the Functional Emotional Developmental Questionnaire (Greenspan & Greenspan, 2001). The questions are based on the Functional Emotional Developmental Levels (FEDL). See Table 9. Parents were very familiar with these levels as they provided the fundamental concepts and goals for the early intervention.

Table 9

Functional Emotional Development Levels (FEDL)	
Functional Emotional Developmental Level	<u>Emotional, Social and Intellectual Capacities</u>
I. Shared attention and regulation	Experiencing affective interest in sights, sound, touch, movement and other sensory experiences. Modulating affects (i.e., calming down).
II. Engagement and relating	Experiencing pleasurable affects and growing feelings of intimacy in the context of primary relationships.
III. Two-way intentional, affective signaling and communication	Using a range of affects in back-and-forth affective signaling to convey intentions (i.e., reading and responding to affective signals).
V. Creating symbols or ideas	<ol style="list-style-type: none"> 1. Using words and actions together (ideas are acted out in action, but words are also used to signify the action). 2. 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; in the second, it is more a signal for something going on inside that leads to a consideration of many possible thoughts and actions. 3. Using somatic or physical words to convey feeling states (“My muscles are exploding,” “Head is aching”). 4. Using action words instead of actions to convey intent (“Hit you!”).

Functional Emotional Developmental Level	<u>Emotional, Social and Intellectual Capacities</u>
	5. Expressing global feeling states (“I feel awful,” “I feel OK,” etc.). 6. Expressing polarized feeling states (feelings tend to be characterized as all good or all bad).
VI. Building Bridges between Ideas: Logical Thinking	1. Expressing differentiated feelings (gradually there are more and more subtle descriptions of feeling states, such as loneliness, sadness, annoyance, anger, delight, and happiness). 2. Creating connections between differentiated feeling states (“I feel angry when you are mad at me”).

The FEDQ parallels the FEDL and is designed to assess the emotional, social and intellectual capacities of the child. It asks the parent to rate each of the capacities from 1 – 7, with the highest rating a parent could give his or her child is a 7. The results are described below and summarized in Table 10. As will be seen, the ratings were very consistent, with only small variations until questioned about future plans where the ratings of younger children who did not have defined thoughts yet lowered the average.

Regulation and Shared Attention

We asked parents whether or not their child could stay focused and calm when doing what he wanted to do (mean=6.9) and also if he was able to remain focused and calm when asked to do something that was not necessarily what he wanted to do, such as homework or chores (mean=6.5). In both cases, parents rated their children as having excellent regulation and shared attention.

Engagement

When asked if the children were engaged overall and the parents reported a 6.9 average. When asked if they stayed engaged when they were upset, angry, or disappointed, the average rating of engagement under emotional stress was 6.1.

Two-Way Intentional Affective Signaling and Communication

We asked parents if their children could show their emotions in more gestural ways and if they could get an interactive flow of communication and interaction going and sustain it. The parents reported that the children could, with an average 6.9 rating.

Social Problem Solving

The children's abilities to engage in complex, shared, social problem solving also got very high ratings (mean = 6.8). The youngsters were all able to sustain the back-and-forth interactions and could have very long conversations. They could not only say what they wanted, but also what they thought and what they thought of "you."

Creating Symbols and Ideas

In terms of emotional ideas, the parents reported that the children could express their feelings and ideas (mean = 6.6). What was most striking is that most of these children went from playing "on the floor" to being wonderful, creative writers and dramatists. As the parents saw them – the children in the follow-up study could express both feelings and motives and demonstrated understanding and "theory of mind" capacities at the highest levels.

Higher Order Thinking

When we looked at higher levels of thinking, we saw a little variation because the children ranged in ages from 12 to 18 years. When it came to understanding multiple causes of behavior in themselves and others; understanding when they felt different in different situations and why they felt that way; judging their own and others' emotional reactions; being able to reflect on their own internal standards; and being aware of their bodies and the impact of the change on them (these were adolescents going through puberty), the results showed ratings above 6 in all these areas. The children's plans for the future were a little less clear, as seen with the mean = 4.4 rating. However, those who were older than 16 years of age were much more defined in their thoughts of the future. Questions about independence regarding important decisions also received slightly lower scores, which is to be expected. These children were aware that big life decisions were going to be made with their families.

Table 10

Parent Rating – Functional Emotional Developmental Levels*	
<i>Derived from FEDQ</i>	<i>Mean</i>
<u>Regulation and Shared Attention</u>	
1a – Calm/focus/able to perform task of choice	6.9
1b – Calm/focus/able to perform requested tasks	6.5
<u>Forming Attachments and Engaging in Relationships</u> with warmth, trust, and intimacy across full range of emotions	
2a – Stay engaged when upset	6.1
2b – Typical engagement/warmth	6.9
<u>Intentional Two-Way Affective Communication</u> – purposeful continuous flow of interactions with gestures and affective reciprocal interactions	
3 – Response to emotional gestures	6.9
<u>Complex Social Problem Solving</u> – able to problem solve through social interactions in a continuous flow using long sequences	
4a – Length of sustained back/forth interaction	6.8
4b – Communicating needs	6.8
<u>Emotional Ideas</u> – able to represent or symbolize intentions, feelings and ideas in imaginative play or language using words and symbols (representational capacities and elaboration)	
5a – Expressing range of feelings	6.6
5b – Create story line with motives and emotions	6.6
<u>Emotional thinking</u> – bridges and combines ideas to become logical and abstracts feelings	
6 – Explains complex feelings	6.6
<u>Higher Level Capacities</u> –	
7 – Understanding multiple causes of others’ behavior	5.3
8 – Varying feelings for one situation (13/16)	6.1
9 – Judging own emotional reactions (13/16)	6.4
10a – Internal standard for self re education	6.1
10b – Role in peer relationships	6.1
10c – Bodily changes-awareness	6.4
11 – Plans for future	4.4
12 – Independent judgement re important decisions	5.2
* On a scale of 1 – 7 with 1 being the lowest score and 7 being the highest score	

Clinician Ratings of Functional Emotional Developmental Capacities

When the clinicians (the authors and research assistant) rated the same children, whether through videotapes, verbal interviews, or recordings, their ratings were very close to the parent responses for all the core capacities. It is important to note that the clinicians rated the children separately from the parents using parallel rating scales. See Table 10.

Table 11

Clinician and Parent Independent Ratings* Functional Emotional Developmental Levels		
	<i>Clinician Mean</i>	<i>Parent Mean</i>
Self Regulation	6.7	6.7
Relationships	6.9	6.5
Purposeful Communication	6.8	6.9
Complex Sense of Self	6.4	6.8
Representational	6.4	6.6
Emotional Thinking	6.4	6.4
<ul style="list-style-type: none">• On a scale of 1 – 7 with 1 being the lowest score and 7 being the highest score.		

We also had the clinicians rate (based on the interviews) the level of empathy (whether it was compared to peers or to siblings), creativity, and talent. This provides a picture of the full range of competencies of these children.

Table 12

Additional Clinician Scales	
N=16	<i>Mean</i>
Empathic (compared to peers)	6.4
Empathic (compared to siblings) (n=15)	6.1
Creativity (compared to peers)	6.0
Talents (compared to peers)	5.7

Achenbach Scales (CBCL)

To obtain an independent measure of functioning, we asked the parents to complete the Achenbach Scales (Achenbach, 1991). Three measures of competence are examined. See Table 13. On the social competence scales, 94% were in the normal range; 88% were in the normal range for activities; and for school competence, results were similar with 88% in the normal range. Two children in this group had learning disabilities (LD) (one was in an LD school and the other home-schooled). The overall competence ratings were 82% with only 18% presenting some variations.

Table 13

Achenbach CBCL T-Scores – Competence Scales (N = 16)			
	<i>Normal</i>	<i>Borderline</i>	<i>Clinical</i>
Social Competence	94%	6%	
Activities	88%		12%
School	88%	6%	6%
Overall Competence	82%	12%	6%

When we looked at the CBCL syndrome scales, see Table 13—clinical signs of anxiety, depression, withdrawal, socially acting out, or aggression—we found, by parent report that 75% fell into the normal range. Thirteen percent were in the borderline clinical range and 12% in the clinical range. However, children showing anxiety and depression, or slight withdrawal from activities and depression are typical of many adolescents during their teenage years. In our study,

those who evidenced anxiety and depression, however, were very verbal and creative. The symptoms were circumscribed and easily managed.

The vast majority of adolescents in the follow-up study showed very good scores in the normal range. One of the children had somatic complaints and seemed to feel somewhat insecure about his changing body. Seventy-five percent showed no social problems, with the rest showing some, and two showing more significant problems.

Table 14

Achenbach CBCL T-Scores – Syndrome Scales			
	<i>Normal</i>	<i>Borderline</i>	<i>Clinical</i>
Anxiety/Depression	75% (12)*	13% (2)	12% (2)
Withdrawal/Depression	82% (13)	12% (2)	6% (1)
Somatic Complaints	94% (15)	6% (1)	
Social Problems	75% (12)	12% (2)	12% (2)

*The numbers in parentheses show how many children under 16 that we had the data set on were involved.

Thought problems were reported for three children. (For a full explanation of these thought problems please refer to the Achenbach scale.) With regard to other challenges: ninety-four percent showed no difficulties in attention. Perhaps it's because of those long back-and-forth conversations that are emphasized in the DIR program. There were no indications of rule breaking, aggression, or other problems.

Table 15

Achenbach CBCL T-Scores Syndrome Scales		
<i>Challenge</i>	<i>% in Normal Range</i>	<i>% in Problem Range</i>
Thought Problems	82% (13 children)	18% (3 children)
Attention Problems	94% (15 children)	6% (1 child)
Rule Breaking Behavior	100%	0%
Aggressive Behavior	100%	0%
Other Problems	100%	0%

Early and Later Motor and Sensory Processing Patterns

It is now well known that children on the spectrum experience significant sensory processing and motor planning difficulties. These challenges can significantly affect self-

regulation, purposeful behavior and adaptation to the environment as well as relating and communicating. Table 16 highlights the high incidence and pervasiveness of these challenges in the 200 cases. As can be seen, all the children in the original study had significant problems with motor or sensory processing and all had some motor planning challenges. We later found that only 18% of the “very good to outstanding” outcome group had significant motor planning problems and that they tended to have more hyper or mixed reactivity to sensation and a lower incidence of under-reactivity compared to the poor outcome group. This finding suggested that children in the better outcome group were more purposeful and capable of planning and executing (sequencing) ideas, and perhaps more likely to react or respond to the environment.

Table 16

Muscle Tone, Motor Planning, and Sensory Reactivity			
N=200 Chart Review (1997)	<i>All Groups Presenting Patterns N =200</i>	<i>Outcome Group Good to Outstanding (58% of N 200)</i>	<i>Outcome Group Poor (17% of N200)</i>
Low muscle tone	17%	12.5%	23.5%
Significant motor planning problems	100%	18%	78%
Underreactive to sensation with patterns of:	99%	30%	48%
Craving/Stimulus Seeking	11%	7%	15%
Self Absorption	28%	23%	33%
Hyperreactive to sensation	19%	25%	15%
Mixed patterns of reactivity to sensation (hyper- in some areas like sound and hypo- in other areas like pain or touch)	36%	45%	37%

We were very interested in finding out what happened to these patterns 10 to 15 years later to learn more about the residuals of these early challenges as the children matured. We asked parents to rate their children using the Sensory Motor Questionnaire (Greenspan & Greenspan, 2001) and they reported that most of the sensory reactivity challenges resolved. Continuing sensitivities were reported regarding pain (47% were still hypersensitive); smell

(33%); and taste (50%). But only some of the children, many of whom had been very picky eaters as young children, were still picky eaters. See Table 17.

Follow Up Profiles

Table 17

Sensory Motor Profiles – Sensory Domains N=16			
Outcomes for Follow-Up Group	<i>Normal</i>	<i>Hypersensitive</i>	<i>Sensory-Seeking (Craving Sensory Input)</i>
Sounds	87%	13%	20% at times
Visual Sensation	80%	20%	13% at times
Tactile Stimulation	93%	7%	33% at times
Pain Sensation	53%	47%	
Smell Sensation	67%	33%	
Taste Sensation	50%	50%	14%
Motion (Vestibular)	93%	7%	29%

Overall, an impressive 88% resolved auditory, visual, tactile, and vestibular hypersensitivities with the benefit of maturation, treatment, and activities. Of those with mixed profiles, we saw 22% still sensory seeking. These children also tended to be more active athletically, which seemed to be a good solution.

Motor planning or sequencing is very much at the core of many of the deficits children with ASD show and may remain a challenging area for children who show the remarkable development this follow up group did. On follow-up, parents reported 40% were still below average on gross motor skills. They preferred playing individual sports and played tennis and/or enjoyed swimming or track. Others with better motor planning were able to do more team sports. Some children with better visual-spatial than visual-motor processing capacities preferred strategy games, such as chess.

The challenges with fine motor planning were manifest in part with difficulties in executive functioning. Some children had better ways of compensating than others. Sixty percent had poor handwriting but they learned to type very well. They also had difficulties managing

time (related to sequencing) and the ability to follow multiple complex directions still remained an issue for some. However, they had greater strength in verbal sequencing, or the ability to organize and elaborate on verbal ideas (in contrast to motor execution). Memory was an important asset and most were very good at visualizing their families, searching for what they wanted, orienting in space and attending to details. More than half (60%) were described as big picture thinkers and able to maintain long logical sequences. Overall, we still saw affect, (i.e. emotional interests), driving improved sequencing capacities and attention to details. Tables 18-21 summarize the findings.

Table 18

Summary of Sensory Reactivity N=16	
Resolved auditory, visual, tactile, and vestibular hypersensitivities	88%
Continued to be hypersensitive to pain and taste	49%
Continued to be hypersensitive to smell	33%
Evidenced some sensory seeking	22%

Table 19

Sensory Motor Profiles - Sequencing N=16			
	Average +	Below Average	Very Poor
Gross Motor Skills: The 40% who were below average on gross motor preferred individual sports and strategy board games	60%	40%	
Fine Motor Skills: The 60% rating below average and very poor on fine motor skills, e.g., handwriting	40%	40%	20%
	Average +	Below Average	Very Poor
Gross Motor Skills: The 40% who were below average on gross motor preferred individual sports and strategy board games	60%	40%	
Fine Motor Skills: The 60% rating below average and very poor on fine motor skills, e.g., handwriting	40%	40%	20%

Table 20

Summary of Sequencing Related Functions N=16	
	<i>Average and Above</i>
Verbal Elaboration and Abstraction	73%
Multiple Directions	60%
Orientation in Space	80%
Visualize Family	92%

Table 21

Summary of Sequencing Related Functions N=16			
	<i>Mostly</i>	<i>Sometimes</i>	<i>Rarely</i>
Multiple Directions	60%	34%	6%
Logical Arguments	60%	40%	
Main and Sub points	60%	40%	
Wide Range Elaboration	87%	7%	6%
Visualize Family	92%	8%	
Systematic Search	80%	20%	
Big Picture Thinking	66%	27%	8%
Good with Details	93%	7%	

Academics and School Report Cards

Parents reported that this group of wonderful young individuals were gifted in math, science, and music. They were very creative and enjoyed a wide range of activities at school. See Table 22. When asked what the challenges were in language arts, the parents were able to tell us that at first many of the children had to work a little harder on getting hidden meanings and making inferences, but were able to master these reflective thinking skills. Two children had difficulty learning to read. But, as can be seen, they progressed in language arts, with 83% average or above average. With respect to math and science, parents reported greater strengths with 62% performing in the superior and gifted range. Similarly, they reported 62% performing in the superior range in social studies and history. See Table 22. Overall, parents reported very high performance in all academic areas.

We also reviewed school report cards obtained from nine of the children.² We found that 83% of this group were receiving all A's and B's in programs which included honors and advanced placement (AP) classes. On the 9 complete reports, there were only two C grades. Sometimes the children were good both in math and English and other times they were stronger in one than the other. Many got A's and B's in science, history, social studies, and languages (some were even studying Latin). See Table 23.

Table 22

Academics: School Reports 8 – 12 th Grades Parent Reports on Entire Group (N=16)	
<u>Math and Science</u>	23% - Gifted 39% - Superior 38% - Average
<u>Social Studies – History</u>	62% - Superior 38% - Average
<u>Language Arts</u>	30% - Superior 53% - Average 15% - Below Average* 46% - Truly love reading 46% - Creative Writers
*Reading comprehension – “getting hidden meanings,” making inferences relatively weaker; reading mechanics still hard for two with learning disabilities	

² This is a preliminary report and follow up will attempt to complete this information

Table 23

<p style="text-align: center;">Academics: School Reports 8th – 12th Grades Fourteen (of 16) were attending high level public and private academic programs. One was in school for LD-Dyslexia. One was home-schooled N=9</p>	
	<i>Independent School Reports (n=9)</i>
Receiving all As and Bs in programs including honors and AP classes (only 2 C grades in this group)	77%
A's in Math	89%
A's in English, language, creative writing	89%
A's and B's in Science	89%
A's and B's in History and Social Studies	89%
A's and B's in Foreign Languages, including Latin	89%

Only one third of the children underwent IQ testing and those had average to superior scores. Most of the scores were balanced between verbal and performance areas, but a few showed large discrepancies with higher verbal and lower performance scores (i.e., lower on motor planning and visual-spatial processing).

Family Stress and Coping

The parents told us there had been stress in their marriages and families. They had to work hard and often needed to be reminded that they were a couple, apart from their child, and needed to take care of themselves. Most marriages did stay together and in some cases relationships improved as couples mobilized to take care of their child's special needs. The early stressors had to do with, "Did I find the right school?" "Did I have the right program?" Parents said that what helped them most in the early years was learning how to be an advocate for their children—being able to speak up and get the educational programs and services needed. Siblings often expressed a concern early on about what they were going to have to do for their little sisters or brothers and needed reassurance. Within the DIR model of family intervention, siblings were usually seen and parents, siblings and the challenged children were all encouraged to express and reflect on their feelings

Looking Back at “Life on the Floor”

What is it like looking back at life “on the floor?” Families polled said that they did an average of nine hours of Floortime each week. The range went from two to sixteen hours per week and as the children got older, that amount of time diminished. The average number of years they “lived on the floor” was almost five (2.5 to 10.4 years). When we asked, “How well did you actually do it?” and “Did you really do it?” on a scale of 1-7 (1 being the least and 7 being the most), self-reports averaged 5.75. When we asked how helpful it was, especially compared to all the interventions they tried or were doing, 88% reported that it was the most helpful.

The Future

In considering the future, parents felt their children would be able to make the best decisions for themselves. What was most important to all these families was how happy, related, and fully involved in life their children were. The parents weren’t thinking about what profession their children would have or what they would do in life; they were most interested in the fact that their children would have relationships, families, and friends, and be able to cope with whatever might come. For example, parents stated:

“I think he will find something he likes to do and will stick with it.”
“When he wants something he usually finds a way to get it.”

In terms of future hopes, one parent stated, “he’s happy and confident; his social skills are in place, academics are strong. He can be whatever he wants to be.” Another said: “I believe the future is open and I believe he will be able to do it all.” These parents were optimistic about the future because their children had exceeded their expectations given what they were told they could expect when their children were first diagnosed with ASD.

Discussion and Conclusions

The children in our follow-up study progressed out of their core symptoms and, more importantly, their core deficits. They became warm, related, and sensitive young people who have the foundations for an optimistic future. They demonstrated competence in a full range of activities. Like other adolescents, however, they were not immune to mental health problems. Some showed anxiety and depression. However, they did not evidence the deficits or symptoms of ASD. While some residual sensory challenges lingered, these did not derail their relating, communicating and thinking abilities. Their progress illustrates the crucial importance of comprehensive and intensive intervention during the early years provided by the DIR model and how a certain group of children can become empathetic, creative, and reflective, with healthy peer relationships and solid academic skills. These children mastered the core deficits and reached levels of development formerly thought unattainable with a family-oriented approach that focuses on the building blocks of relating, communicating, and thinking.

The DIR model provides the framework for implementing such a focus through daily floor time sessions supporting the continuous flow of engagement, symbolic play and higher

order thinking, as well as ongoing problem solving and reality based logical conversations, and reflective “talk time”, play dates and friendships. Parents validated these mechanisms as the most responsible for their children’s improvement. In addition, a wide range of individualized activities and therapies address the critical underlying regulatory and sensory processing challenges. For this group of children the most intensive interventions were provided during early childhood and the benefits continued long after the specific therapies ceased with the building blocks were established. The comprehensive nature of the intervention and the intensive level of daily interactions integrated relating, communicating and thinking into the fabric of every child’s and family’s life.

We will continue to follow this group and also conduct follow-ups with additional children who have done very well. Furthermore, we will be conducting follow-ups with children who have made slower progress. In many respects, their gains are even more remarkable because of the greater hurdles they have had to overcome.

It is important to emphasize that whenever we report on a subgroup of children that did outstandingly well, it is always with trepidation, knowing that there are many families who are working hard with their children and not seeing the kind of progress that this subgroup experienced. And, again, we don’t know how representational this population of children with ASD is and how many others share the characteristics of this group. We can note that children with slower or less progress, as reported in our 1997 study of 200 cases, are also making gains in their core deficits. They are learning to become engaged, interactive and communicative, but with more limitations in their language and reflective thinking capacities. We have also worked with adolescents and middle aged adults with ASD and observed progress (Greenspan & Mann, ICDL guidelines, 2000).

The most important lesson is that progress can continue into the adolescent years and further. Therefore, it is most important to continue to try to work with the child and his or her family on these most essential capacities for relating, communicating, and thinking. When we observe that a subgroup can make these kinds of gains it is encouraging. Such observations suggest that we are harnessing the essential developmental processes in using the DIR/Floortime model. The fact that a subgroup can move to a level of creative and abstract thinking thought unattainable even by “high-functioning” children with ASD suggests that we are mobilizing critical aspects of emotional and intellectual growth.

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