

Empowering families through Relationship Development Intervention: An important part of the biopsychosocial management of autism spectrum disorders

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BACKGROUND: Relationship Development Intervention (RDI®) is a program designed to empower and guide parents of children, adolescents and young adults with autism spectrum disorders (ASD) and similar developmental disorders to function as facilitators for their children's mental development. RDI teaches parents to play an important role in improving critical emotional, social, and metacognitive abilities through carefully graduated, guided interaction in daily activities.

METHODS: The paper reviews RDI's theoretical underpinnings, current methodology and preliminary research results. The clinical utilization of RDI is discussed as an important part of the biopsychosocial management of ASD.

RESULTS: Although a controlled, blinded study of RDI has yet to be done, preliminary research suggests that parents, through the RDI curriculum and consultation process, have the potential to exert a powerful impact on their ASD children's experience-sharing communication, social interaction, and adaptive functioning.

CONCLUSIONS: RDI should be considered as part of a comprehensive treatment regimen, in which the physician plays a clinical management role, providing medical and psychiatric consultation. The RDI clinician can function as a remediation specialist, providing accurate feedback to the physician, along with individualized training and guidance to family members.

KEYWORDS: autism, intervention, parents, quality of life

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INTRODUCTION

It has been nearly 10 years since the introduction of the Relationship Development Intervention (RDI®) program, a family-centered approach to remediating the primary deficits of autism spectrum disorders (ASD).¹ More than 5000 families in 16 countries are currently participating in RDI. Although several books and articles have been written about RDI²⁻⁴ and a Web site (www.rdiconnect.com) contains extensive information about the program, it still not widely known, and most professionals and laypersons have only partial or incorrect information about the program. The purpose of this article is to familiarize clinical practitioners with RDI. Additionally, the article describes ways that RDI can be a useful tool for clinical psychiatrists and pediatricians involved in the biopsychosocial management of children, adolescents, and adults with developmental disorders.

RDI hypotheses

RDI methods are continually evolving. However, the program model is based on 2 specific hypotheses about the nature of ASD:

1. The deficits of individuals with an ASD can be divided into homogeneous “primary” deficits, which define the disorder and heterogeneous “secondary” deficits, which may or may not be present in any particular individual. Primary deficits reflect the failure to develop dynamic intelligence, along with the relatively poor development of dynamic neural functioning.
2. In typical development, dynamic intelligence is built through thousands of hours of a special type of adult-child collaboration referred to by developmental psychologists as the “guided participation relationship.”⁵ For typically developing children and their caregivers, guided participation is an intuitive, universal process originating during the first year of life.^{6,7} However, in children with an ASD, guided participation either never develops or is disrupted early in the child’s development.

Dynamic intelligence as the primary ASD deficit

Recent research is clearly differentiating primary deficits from secondary comorbid characteristics of ASD. For example, speech problems are now perceived as secondary deficits, as only a small percentage of indi-

viduals with ASD never learn to talk, and the majority are quite fluent though highly ineffective communicators.^{8,9} Similarly, the type of intelligence assessed by standard IQ tests—measuring the associations, facts, procedures, solutions, and strategies we have accumulated—is viewed as a comorbid condition, as only a minority of persons with an ASD are mentally retarded.^{10,11} Finally, social motivation and social skills are secondary deficits, as research demonstrates that the vast majority of individuals with autism show a strong desire for social interaction and can learn “discrete” forms of social skills like greetings, setting specific rules (eg, “Don’t talk in church”), and even some “theory of mind” skills, as long as they do not have to continually evaluate and adapt their actions in coordination with others on a moment-to-moment basis.¹²⁻¹⁵

In the current scientific view, autism appears to be a disability primarily involving specific forms of complex information processing,¹⁵⁻²⁷ This deficit in turn results in a host of specific developmental problems in areas such as social collaboration, experience-sharing communication, emotional awareness, episodic memory, real-world problem solving, self-awareness, and self-regulation.²⁸⁻⁴⁷ These problems correspond precisely to the abilities considered components of “dynamic intelligence.”⁴⁸⁻⁵¹ Among other things, dynamic intelligence consists of being able to rapidly analyze, appraise, evaluate, adapt, collaborate, compromise, and innovate. In the real world, problem solving, communication, social relationships, and self-regulation require a continuous process of adapting to uncertainty and change. Attaining even a minimally acceptable quality of life demands that we possess sufficient dynamic intelligence to effectively manage a complex, messy world of partially misunderstood communication, multiple demands and goals, gray areas, makeshift solutions, conflicted feelings, and “good-enough” performance.⁴⁹⁻⁵¹ The dynamic aspects of their world are exactly those that persons with ASD find so baffling and terrifying. Individuals with ASD can accumulate all kinds of knowledge about the world. But often it is useless, because the knowledge does not inform them about what we actually *do* with one another on a moment-to-moment basis. Klin illustrates the dynamic/static deficit distinction for individuals with ASD in the following passage: “The fact that cognitively able individuals with autism are able to demonstrate so much social cognitive information [static intelligence] is as interesting as the fact that they

fail to make use of most of these skills.”⁵²

The case for dynamic intelligence as a primary ASD deficit is supported by recent neurologic research. The hallmark of a well-functioning brain is the ability to form dynamic relationships between different neural processing centers that can be called upon as needed. This allows individuals to consider multiple perspectives for any single problem, setting, or encounter and to forge new pathways when prior solutions no longer suffice. A number of researchers have concluded that the unique neural characteristic in ASD pathogenesis is the failure of the brain to develop an ability for neural collaboration.⁵³⁻⁵⁹ For example, Just et al concluded that the brains of individuals with ASD demonstrate “underconnectivity,” which they define as the inability of different neural processing centers to form ad hoc collaborations as required by novel, complex problems. Instead of greater collaboration, the brains of ASD individuals become more rigidly linked to specific brain centers. Just et al go on to hypothesize that neural underconnectivity could explain the problem of ASD individuals with dynamic kinds of problems and settings in responding flexibly to their environment: “The underconnectivity could explain the difficulty in novel cognitive tasks wherever inter-regional coordination is critical. A novel task requires the underpinning brain regions to dynamically configure themselves into an appropriate network, and the poorer connectivity in autism impairs this dynamic ability.”⁶⁰

Guided participation

Dynamic abilities develop through an intuitive relationship between children and their caregivers that psychologists refer to as guided participation.^{61,62} In the guided participation relationship, children participate with family and community members as cognitive “apprentices,” receiving the guidance and support of caregivers as they encounter new cognitive challenges. The goal of the guided participation relationship is to develop abilities that are genuinely transferable and not tied to a single setting or body of knowledge. Through the thousands of productive encounters constructed from activities of everyday life, the child literally comes to “borrow” his or her guides’ mental processes and learns that he or she can manage multiple perspectives to perceive the world through his or her own as well as others’ eyes and ears.⁶³⁻⁶⁸ During these activities, caregivers consciously or unconsciously de-emphasize the super-

ficial, instrumental product that would be most apparent in the activity (eg, buying the groceries or getting the bed made) and use the activity as a vehicle for seeking out and structuring opportunities for mental discovery, or elaboration of prior discoveries (eg, anticipating items on the next aisle or considering how neatly the bed needs to be made). Guides intuitively choreograph moments where the apprentice experiences heightened but safe uncertainty or ambiguity; when lessons revolve around problems at the “edge” of the apprentice’s competence. Guides foster these experiences by adjusting their actions to help the apprentice remain at the “edge” without overwhelming anxiety, and as a result, both guides and apprentices become highly motivated to remain at this relatively high-tension, high cognitive payoff state.⁶⁸

Guided participation and ASD

A consensus is emerging that ASD is a complex, multiterminated biopsychosocial condition, better understood from a pathogenetic than an etiologic perspective.⁶⁹⁻⁷² One critical implication of the pathogenetic model is that, for each person with ASD, there may a sufficient set of physiologic vulnerabilities manifesting somewhere during infancy, resulting in the child’s leaving the typical developmental pathway and emerging onto an “autism pathway.” Our hypothesis is that the pathogenesis of ASD is the result of infants, at some point in their first 18 months, forfeiting the benefits of the guided participation relationship—the pathway necessary for developing dynamic intelligence—with resulting catastrophic results.

The underlying “engine” of guided participation is the development of intersubjectivity, a progressively more comprehensive communication for emotional attunement and sharing of focus between children and their more skilled partners.⁷³⁻⁷⁸ The early failure of children with an ASD to develop intersubjectivity—including their universal failure to initiate joint attention, a milestone of typical 12-month-old intersubjective development—is the most documented deficit in autism research.⁷⁹⁻⁹² Without the development of at least a modicum of intersubjectivity, guided participation becomes impossible, regardless of the ability of the parent or caregiver. Without an intersubjective stance, infants cannot provide caregivers with the reliable feedback needed to maintain the “edge” experience in which dynamic capabilities are honed. Simi-

larly, they cannot perceive that their actions and the actions of their partners can function in a coordinated manner to create a temporary “we” state.

Once guided participation is disrupted, there is a rapid deviation from normal development. This autistic pathway of development includes an over-reliance on “static” forms of learning, such as accumulating rote information, scripts, and procedures, as well as frequent obsessive involvement with the single or few areas of interest or competence that the child considers safe. Uncertainty and challenge is perceived as something to avoid at all costs. Both child and caregivers seek out sameness and accumulation rather than discovery, integration, and expansion. “Don’t rock the boat” becomes the pervasive motto by which families survive.

Principles of RDI

Four basic principles guide the development of the RDI program: (1) providing a second opportunity to develop the guided participation relationship, (2) investing in families first, (3) careful developmental construction of dynamic intelligence, and (4) biopsychosocial management of comorbid conditions. The following section briefly describes each of these concepts.

1. Providing a second chance for the guided participation relationship

As the prior section illustrates, the foundation of RDI is our belief that ASD are the consequence of neurologic and other biomedical vulnerabilities that, in combination, permanently disrupt the guided participation relationship early in life. We believe that if we can provide a second chance to restore or establish guided participation in a more deliberate, “mindful” manner, while simultaneously lessening the continuing impact of biomedical and other comorbid problems, we can help the majority of children with ASD and their families embark on a more normal path of cognitive, emotional, and social development. We believe that most individuals with an ASD are born with some capacity to participate in guided participation. Although this capacity is overwhelmed at some point in early development, we believe it has the potential to become available again under the right circumstances.

2. Investing in families

Given our belief in restoration of the guided participation relationship, it is no surprise that we feel that the

child’s natural caregivers should be the recipients of the bulk of service resources: Our definition of caregivers includes parents, grandparents, uncles, aunts, and close social relations who function as important long-term members of the family’s social network. The goal should not be to turn family members into therapists but, rather, to guide them to develop new ways of thinking, perceiving, and acting to know how to best use their time in facilitating the child’s mental growth.

3. Carefully building dynamic intelligence

Although learning dynamic intelligence is difficult for individuals with an ASD, these abilities are essential for attaining an optimal quality of life. A useful curriculum for building such complex mental capabilities requires a very systematic, developmentally based approach, starting with the earliest foundations and then sequencing the gradual construction of hundreds of more complex abilities. Mastery must come from the “bottom up” in a developmentally appropriate manner. And we have to recognize that these are mental skills—new ways of thinking, perceiving, and feeling—not simple behaviors.

4. Biopsychosocial management

The pathogenesis model of autism describes how many different physical conditions can combine to create a “threshold effect” that disrupts guided participation. However, it does not assume that the initial etiologic factors fade away after autism has emerged. In fact, they often remain as “comorbid” conditions that can at times function as greater obstacles to development than the autism itself.^{93,94} A host of biomedical and neurologic problems, ranging from severe allergies and intolerances and immune deficiencies to seizures and seizure-like disorders, may significantly impede the ability of the child to be available for guidance. Similarly, psychiatric conditions such as attention-deficit/hyperactivity disorder, obsessive-compulsive disorder, generalized anxiety disorder, and oppositional defiant disorder, can create enormous obstacles.^{95,96} An evaluation and treatment partnership is essential between the RDI family consultant and the physician specializing in pervasive developmental disorders. The partnership works in several important directions.

Ideally, the physician assumes the role of biopsychosocial team manager as well as medical expert. The RDI consultant functions as a remediation specialist, guiding day-to-day remediation, as well as “clearing the

smoke,” by providing the physician with the information necessary to provide appropriate medical and psychiatric diagnoses and ongoing care.

As the medical expert, the physician can diminish the impact of medical conditions so that the family can more readily take advantage of opportunities for remediation. Although parents definitely do not cause autism, the crisis of diagnosis and living with an autistic child creates the environment for sometimes debilitating depressive and anxiety disorders, which are common in parents of autistic children.⁹⁷⁻⁹⁹ A good number of parents may also suffer from symptoms that, if not identical, are similar to those found in posttraumatic stress disorder.¹⁰⁰⁻¹⁰² Parents may become physically over-enmeshed with their child and classically conditioned so that even the slight expression of distress on their child’s part leads to an immediate jump of 60 to 80 beats per second in their heart rate and a resulting panic reaction. It is quite common to hear complaints similar to the following: “I know it’s not my fault. I know I didn’t cause my child’s autism. But to tell you the truth, it doesn’t really make much difference. It doesn’t reduce the pain I feel every time I try so hard to make some basic contact, to do what everyone else can do so easily, and fail for the millionth time.” In all of the above cases, sensitive psychiatric treatment often provides the only means for parents to be able to successfully participate in RDI.

Training programs

We have developed 3 training programs to address the learning needs of parents and professionals seeking to be effective guides: (1) parent readiness, (2) guided participation, and (3) consultant training.

1. Parent readiness

This is a systematic but very customizable way of helping parents recover from the loss of self-efficacy and immense stress resulting from the failure of guided participation and the day-to-day stress of living with an ASD child. Without realizing it, many parents have given up hope of functioning as guides and have substituted being an advocate for their child as their primary role, using up all of their energy in fighting for more professional services. Some are spending almost all of their available parenting time driving their child from one therapy appointment to another. Others do not realize that they can set normal limits and bound-

aries with their ASD child. For example, they may need to learn that even if their child is trying to push away, parents do not have to let go. Many parents believe that the best they can do is to keep their child entertained and to provide a learning environment that focuses only on static abilities.

The parent readiness curriculum seeks to rebuild parents’ faith in their own competence, so that they can take the risk of trying a second time to function as guides for their child. Essential elements of the program include providing a meaningful quality of life for each family member, learning to set and maintain appropriate limits, maintaining a healthy marriage, and finding time to slow down routine daily activities. The program also teaches parents to differentiate actual research findings from myths that abound in the autism community.

2. Guided participation program

Parents attend the guided participation program after “graduating” from parent readiness, whereas teachers and other caregivers may begin their training with this program. The program has more than 40 objectives, covering such areas such as altering communication style (eg, using fewer words, using predominantly experience-sharing communication, emphasizing non-verbal communication channels, and slowing down communication to allow time for processing). Guides learn to focus on the process of their interaction with the apprentice rather than the outcome. They also learn how to modify activities in order to maximize their usefulness in mental development and to present productive cognitive challenges by carefully evaluating the “edge” of their child’s level of competence.

Parents learn to incorporate the assignments provided by their consultants into everyday activities. In addition, they learn to document their progress and analysis and to maintain ongoing communication between sessions, using the RDI “operating system” for online charting and communication, tools described in the next section. This creates an ongoing dialogue between parents and consultants. Parents learn to select video representations of their efforts to upload to consultants for analysis and feedback and to use the virtual community and educational tools (eg, webinars and forums) for continuing education and emotional support.

3. Consultant training

This is a structured program for RDI consultants in

training. Professionals involved in training have varied backgrounds (eg, psychologists, social workers, occupational therapists, and speech pathologists). They spend an average of 12 to 18 months learning to function as “guides to the guides,” helping caregivers learn to modify their communication, slow their pace, and focus on the underlying opportunities available in their daily routines. Consultants learn to sensitively approach each family, based on their readiness and unique needs. Training includes expertise in gradually transferring guided participation methods to parents, family members, and teachers.

Consultants learn to effectively use their live consultation sessions with clients, held at approximately 2-week intervals, for planning and critical troubleshooting. They learn how to video record critical moments of their sessions so that parents can continue to review them at home. Additionally, they learn to manage the online communication and feedback system, whereby they provide clarification and make adjustments and modifications between sessions. Following certification, consultants have rigorous, ongoing continuing education and quality assurance requirements. As of this article’s publication, there are 202 certified RDI consultants, with an additional 224 in the training process.

Professionals from 16 countries (including China, Japan, Poland, Mexico, Turkey, and South Africa) have trained as RDI consultants to be able to bring the program back to their nations. Consultants learn to modify methodology to optimally reflect cultural norms. For example, in Singapore, both parents almost universally work. However, grandparents are typically available and close by and thus play an especially prominent role in the program.

RDI tools

Along with the aforementioned curricula, we have developed 3 critical RDI tools, addressing different aspects of the remediation process. These are (1) the Dynamic Intelligence Curriculum, (2) the Relationship Development Assessment (RDA), and (3) the RDI Learning System (RDI_LS). The following section briefly describes each of these tools.

1. *Dynamic Intelligence Curriculum*

This curriculum encompasses the developmental sequence by which abilities like communication monitoring, emotional self-regulating, social coordination,

problem appraisal, and interpersonal collaboration are “discovered” by the apprentice and gradually elaborated upon, to be used in more fluid and integrated ways. Simultaneously, the curriculum sequences the way that dynamic processes move from primarily externally relationship-bound abilities, eg, social referencing (checking to determine the reactions of a familiar adult when uncertain), to internally self-contained equivalents, eg, self-referencing (when uncertain, relying on your own past experiences). Finally, the curriculum provides a developmental pathway corresponding to the manner in which typically developing children gradually learn to independently manage the complexities of these processes with their own minds, in increasingly diverse and complex settings and with increasingly diverse and more complex partners.

Development of this curriculum began by the author painstakingly “deconstructing”—analyzing the underlying elements—of scores of complex dynamic processes and breaking them into their simplest forms or “prototypes.” Using the findings of hundreds of research studies in typical development, these initial prototypes were then organized into a logical sequential structure of 12 stages and more than 1000 detailed objectives. Each objective is carefully described and includes observable mastery criteria and links to specific processes and goals.

2. *The RDA*

The RDA is a planning process, conducted approximately every 6 months. It provides an opportunity to examine the family as a whole, while they conduct guided participation. During the 6-stage process, consultants evaluate the current state of guided participation and then systematically attempt to determine obstacles that may be impeding its development. Finally, consultants develop plans to join with the family, at whatever level of readiness they present, to overcome their unique obstacles and meet their unique learning needs.

3. *The RDI_LS*

Another critical piece of the RDI program was implemented in December 2007, with the launch of an online worldwide virtual learning and support community. The RDI_LS is a sophisticated, Web-based application that allows users to do many things that were previously impossible. Parents, caregivers, teachers, and consultants-in-training can find thousands of targeted

resources and E-learning courses. They can attend online webinars held multiple times weekly. All of the child and parent objectives are found online, along with a continually growing resource library. This library contains thousands of video representations of progress and mastery, with each video clip indexed by the specific objective it represents, so parents can review videos that are directly relevant to their current objective. With parental consent, consultants are continually contributing video examples to the common subscriber library. Video clips, with accompanying explanations, are indexed by objective, age of child, nationality, and language spoken, among other factors.

Parents can effectively communicate with their consultants to track their progress and receive feedback on a regular basis. Every member learns to regularly send “work products,” which consist of short video files along with their thoughts and analysis. Work products represent parents’ concerns and frustrations, highlight their progress and mastery, and respond to specific assignments written by their guides. Consultants respond online to work products and provide valuable feedback during the interval between live meetings. The ongoing communication process between consultant, parents, and other team members is chronologically displayed and stored in the family’s online virtual chart, along with videos and associated analyses. Additionally, users have access to a wide range of reports to examine current objectives, track progress, and plan future treatment.

Using the RDI_LS for medical management

Medical managers can use the RDI learning system in several ways. First, they can obtain real-world video samples of their patient’s functioning in a variety of settings. Parents and teachers are trained to create and upload relevant video clips in short, succinct segments, so problems and symptoms can be viewed directly by the psychiatrist, rather than indirectly through parental or teacher report. The RDI_LS can provide the physician with accurate baseline observations and time-stamped video clips unfolding day-by-day in varied situations. The physician can, if desired, write assignments to the learning system in order to obtain specific samples of behavior needed for proper diagnosis and medication monitoring.

Physicians can receive regular customized progress reports with as much or as little detail as desired. Reports can provide summaries for a single patient or a group of

patients. Reports can detail specific objectives that have been mastered and short, intermediate, and longer-term objectives customized for each patient’s needs.

RESEARCH

Controlled, double-blind research of RDI effectiveness is still needed. However, a recently published research study demonstrated preliminary findings about the effectiveness of RDI. The study followed 16 children whose families participated in the RDI program for a minimum of 2 years.¹⁰³ At their initial pre-RDI evaluation, 15 of the children required special education classrooms. At the time of the follow-up evaluation, only 3 of the 16 children still required special education classes or a one-on-one aide. Prior to RDI, 14 of the 16 children were rated as functioning in the autism range on the Autism Diagnostic Observation Schedule (ADOS) and Autism Diagnostic Interview-Revised (ADI-R). After an average of 2 years, only 2 of these children still received the autism rating on either instrument.

Parents engaged in RDI overwhelmingly report significant improvement in their own quality of life, as well as the lives of their nonaffected children. For example, parents as a group reported at onset that their children were able to manage sudden changes and transitions like comparably aged, nonaffected peers about 16% of the time. By the follow-up point, parents reported that their child with an ASD handled situations requiring flexibility over 70% of the time as well as they would expect from a typically developing child.¹⁰³

CONCLUSION

In the 10 years since its introduction, the RDI program has become one of the preeminent relationship-based tools for autism interventions. Currently, more than 200 RDI consultants care for more than 5000 families in 16 different countries.

RDI consultants, with their training and emphasis on family support and customized parent training, offer a natural collaborative relationship for physicians wishing to provide quality care from a biopsychosocial perspective.

The remedial focus of the program—systematically addressing the dynamic cognitive deficits to provide the

means for individuals with ASD to climb the otherwise impenetrable wall to attaining an acceptable quality of life—fills an otherwise neglected niche in the arsenal of medical strategies that have potential to provide real-world results over the long term.

Clearly, further research is needed to demonstrate the program's efficacy. Work is needed to pinpoint which children and families will benefit from this approach. Studies are needed to “deconstruct” the comprehensive program to determine which program elements are most related to its success.

Outcome research is still in its infancy, as with

all autism-related interventions. However, the sound, proven principles that RDI is based—such as investing in family empowerment, training parents to reconstruct their natural “guide” relationship, providing a large worldwide support community, systematically addressing critical information processing deficits from a developmental perspective—provide a good rationale to the belief that the RDI program offers considerable value.

DISCLOSURE: Dr. Gutstein is an employee of RDIconnect, Inc.

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