

PUZZLE PIECES

Spring 2000



Notes from the Director Case Management Meryl Lipton, M.D., Ph.D.

Recently, while sitting at a coffee shop, I couldn't help but overhear an important conversation. It helped me better understand some repeated struggles I often

hear from the parents of my own patients, children with brain-based learning and social problems. I will paraphrase what I heard.

Two women were candidly discussing problems they were having with their children. One of the children was diagnosed with a learning disability at the age of 7. The parents received a 20-page written evaluation which was reviewed with them and included a vast list of recommendations for the family and the school. A tutor started working with the child two days a week. Initially, school services were provided but then discontinued because "he was doing so well." The child is now 9 years old, problems continue at school and now there are problems at home. This year's teacher states "he would do better if he just worked harder."

The mother of this child was in a quandary. She said that she never really understood the 20-page report and couldn't figure out which of the 11 recommendations to follow, or even which to start with. The tutor was chosen due to convenience as she lived next door and had room in her schedule. Now, the child is older and the mother was wondering if the same recommendations would be useful.

In one way or another, parents of my patients talk painfully about being in the same situation. They've told me about taking their children with neurobehavioral disorders to physicians, psychologists or educational diagnosticians. The diagnosis is determined, explanations are offered and the family is given some recommendations for treatment.

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Social skills group

Joshua F. Mark, LCSW

As a clinical social worker, I have been providing group treatment experiences at RNBC for children diagnosed with nonverbal learning disabilities and related disorders. These children struggle to process social interactions and nonverbal communication on a variety of levels. This nonverbal information, such as facial expressions, body language, personal space, and voice intonation, seems to be implicitly understood to most of us, yet for these children it is an area that must be taught directly.

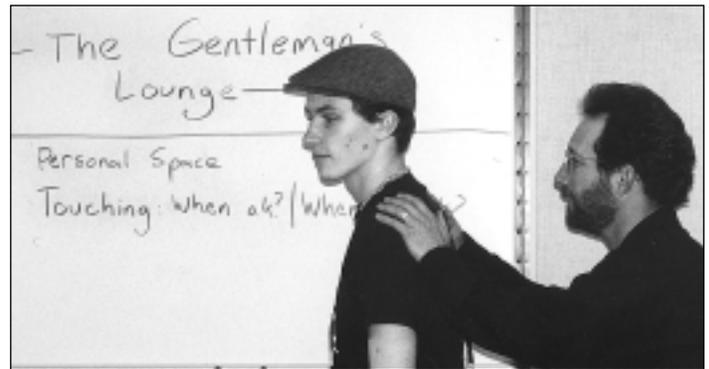
Each of the groups I have led has been comprised of boys similar in age, with a history of struggles in the social realm. In the planning and execution of social skills groups, there are formidable challenges. How can I address both

the social skills deficits and the emotional vulnerability many of these children carry with them? I have found that it is indeed a package deal.

I remember, as I planned a therapeutic approach to the first group, I asked my senior colleague, Joe Palombo, for some advice. Joe said, "Make it a group where you can address their self-esteem." This advice has served me well. The children I work with have often been wounded in the difficult, and at times, cruel world of peer culture. It is an assault to self-esteem to fail again and again.

In planning social skills groups, I focus on creating an environment of trust and openness. In this environment, I am able to help these children improve their social skills and strategies. I encourage sharing of personal struggles. Many discussions address issues such as, why no one sat with me in the lunchroom, the phone call that didn't get returned, the schoolmate who sent an angry email message, or the sleep-over that didn't go so well. This process of sharing enables the children to experience some of the components of social intimacy they often miss. Recently, I was talking about this issue with a former group member who summed it up by simply saying, "The more people you know who have the same problems as you, the more comfortable you can feel, and you know you're not the only one."

Each group session is multi-faceted. Sessions consist of the sharing of life experience, social interaction within the group itself, and development of concrete social skills. Concrete skill development is a critical component of each session. It is a way to explicitly teach these children the very parts of communication which are taken for granted by those of us who have learned these skills naturally and unconsciously. The children learn how to read social information embedded in facial expressions and body language. They learn to be more



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Notes from the Director

Too often that is where the diagnostic process ends. The family is left to communicate the findings to the school, a tutor, a counselor, etc. The family is also expected to oversee the coordination of the child's neurobehavioral interventions.

This approach to care works pretty well in some parts of medicine. For example, if a child has a broken leg, a physician can make a diagnosis and begin the healing process by setting the leg in a cast. The patient is told what to do and what not to do. Over time, the broken leg becomes an event and passes with comparative speed.

But that is not what happens to children with neurobehavioral challenges. Their issues are not an event. They do not end. They are on going, a process, and a way of life. For these children to thrive over time, case management services can be beneficial.

How does the case management process function?

Within the case management model, parents and the patient (when age appropriate) are provided education regarding the diagnosis. Through a long process they come to understand the child's strengths and weaknesses and the relationship between this pattern of abilities and the child's behavioral effectiveness within the family, at school, and in the child's social communities.

With case management, the family receives expert help in choosing the best person for the specific interventions that their child needs. Equally important, they gain seasoned advice in evaluating the success of each intervention. A communication system is set-up and maintained linking the family, the school and the other team members. Education, coordination and communication are key elements in successful case management.

Who can take the role of case manager? Many times families effectively work with a psychologist, a physician, a social worker, or another professional who does case management as part of their role with the family. There are also professionals who provide case management as a separate and specific service. These professionals are experts at maximizing what the child needs and knitting together the activities of family, teachers, health professionals, etc. They are not needed in every child's situation, only in those where the issues are of a complex nature.

Because we believe case management is such an important aspect of providing quality care to children with neurobehavioral issues, we are developing case management services at Rush Neurobehavioral Center. ■

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Social skills group

conscious of voice modulation, eye contact, and personal space. Group members practice more complex social tasks such as starting a conversation, keeping a conversation going, joining a group, and coping with teasing. There are many valuable techniques to teach these skills such as role-playing, observing and discussing social interactions in videos, and looking at pictures which capture feelings and expressions.

For the child who struggles with difficulties in processing social interactions, I have found the social skills groups to be an excellent forum for addressing these very personal, yet developmentally important life issues.

Contact Kate Gonley at 847-933-9339, ext. 222 for more information about RNBC social skill groups. ■

Upcoming Events

Thursday, March 16th...will begin our three-part "Brain and Learning" series at the Harold Washington Library in Chicago. It is intended for teachers. 5-6:30 p.m. For information, call 312-747-4624.

March 24th & 25th Stephen Nowicki, Jr., Ph.D., Meryl Lipton, M.D., Ph.D. and Joe Palombo, M.A. will present at the 4th annual NLD conference in Concord, CA.

Thursday, April 13th "Brain and Learning" series continues at the Harold Washington Library in Chicago. Warren Rosen presents "Right Hemisphere Mediation of Learning and Social Abilities." It is intended for teachers. 5-6:30 p.m. For information, call 312-747-4624.

Friday, April 28th "Neurobehavioral Nursing for the Millennium," a nursing colloquium in the Searle Conference Center of Rush-Presbyterian-St. Luke's Medical Center, Chicago, IL

Thursday, May 11th Final part of "Brain and Learning" series continues at the Harold Washington Library in Chicago. John Bartok, Ph.D., will present. It is intended for teachers. 5-6:30 p.m. For information, call 312-747-4624.

Friday & Saturday, May 12th & 13th Meryl Lipton, M.D., Ph.D., will be a Keynote speaker at a conference entitled "Nonverbal Learning Disability—Putting the Pieces Together" in Alberta, Canada.

Thursday, November 16th Rush Neurobehavioral Center's annual benefit dinner will be held at the Four Seasons hotel in Chicago, IL.

Friday, November 17th Stephen Nowicki, Jr., Ph.D., will hold a workshop for teachers, at Rush-Presbyterian-St. Luke's Medical Center in Chicago, focusing on social learning disabilities. For information, call Kate at 847-933-9339, x222.

" A CELEBRATION OF DIFFERENCES "

AN RNBC EDUCATIONAL VIDEO TAPE

See back page for ordering information



"Booklist"

The American Library Association

"Reverberating with respect and affection for children struggling with these brain-based disabilities, this heartening program will enlighten parents, educators and students" --Irene Wood

The New York Festival of Film

usa today

"It's that raw quality in the film that makes it stand out," says Sally L. Smith, founder of The Lab School of Washington (D.C.), the nation's oldest school for children with learning disabilities, and author of *No Easy Answers*. "It's so real, so unpretentious," The Illinois neophyte filmmakers, she says, captured what the professionals have missed: "The kids themselves talk it through. They're comfortable in their own skins, and they're passionate about it".



Well, I'm determined, like I don't give up on stuff, I just get up and try to work on it, or be better at it, or try to solve it and think what I've done wrong and go back and eventually it's all better again until another problem comes along.

— Alex Mahoney,
8th grade student



Producers accept
"Finalist Award "
in
Guidance & Counseling
1999

SIDE SSIDE by SIDE

Educators, parents and children sharing viewpoints about neurobehavioral disorders

Q.

Melissa is 12 years old and was diagnosed with nonverbal learning disabilities. Melissa isn't reading facial expressions and body language of others. She is having arguments with her parents and can't understand why. Her parents are frustrated with the silliness and inappropriate behavior, and their daughter's lack of response to their correction. ***How would you help Melissa and her parents?***

A. **Jean Newton, M.A.**
Learning Disability
Specialist, Northfield, IL

This child and her parents need intervention that is comprehensive to thaw the difficulties they've developed in their own relationship. The most devastating effects of nonverbal processing differences, when they are severe, are in the areas of social communication and forming relationships. Help is three-fold: Melissa and her family should understand she is "missing" nonverbal cues to social information, and this results in misunderstandings with friends and parents; Melissa needs her parents' help in forming positive relationships with friends; and Melissa could benefit from verbal analysis and scripting of social situations most difficult for her.

After careful interviewing to determine the most typical conditions under which arguments occur, the first intervention for this family is information. Melissa and her parents can be helped to understand what prevents her from getting the whole meaning from any simple interaction. Videos, both classics and contemporary, of adolescents in social settings could be used to make Melissa aware of the nonverbal cues of facial expression, gesture, and posture. (These carry more meaning than the words of a communication. Practice with the effects of "mixed messages" can be fun!) Video tapes can be watched without the sound, then paused to analyze facial expression components such as eyebrow

height, lines in the forehead, and the corners of the mouth.

Next, help in restoring and forming positive relationships with friends and parents should be undertaken. It's a mistake to underestimate the value of these relationships for children. With Melissa, making a visual diagram of friends and acquaintances she experiences in the flow of her week, with single or double arrows to indicate reciprocity, would reveal steady patterns both to her and to her educational therapist.

These patterns would help the two of them to choose appropriate friends for activities both in and out of school. Forming a few closer relationships around shared experiences would buffer the effects of Melissa's frequent arguments and strengthen social skills. Melissa's parents can play an active part in helping her choose activities with friends which promote interaction, provide time limits, and make the arrangements which Melissa herself can't yet coordinate. In this way, they assure success and may begin to see their daughter as increasingly socially competent.

Finally, social scripting may help Melissa. This is an intervention, which is based on verbal mediation and focuses on the strengths of children with weakness in nonverbal processing who may be strong in logic, reasoning, and verbal understanding and expression. In social scripting, the particularly troublesome situations are identified. Often, these include joining a group already at play, or constructing and deconstructing play. Melissa could be taught to recognize

ambiguities in a social interaction among a group of friends, and verbal input, which promotes understanding and a mutual viewpoint. Remarks like, "That's a good idea, and how about this...?" or giving a compliment before a request could be taught to Melissa to help to smooth her social interactions. Her silliness may be a lack of knowledge of what to do. Social scripting and rehearsal provide positive strategies for children, when utilizing nonverbal cues in social communication is difficult.

A. **Loren Deutsch, LCSW,**
M.Ed., Private Practice,
Winnetka and Chicago

As a clinician, I tend to take the perspective that not everything needs to be done at once. Though, as a parent I know that certain situations feel like they need big responses. That said, a nonverbal learning disability (NVLD) diagnosis is complex. There are multiple ways in which a clinician could respond to the above description of Melissa and her parents. It is imaginable that a clinician would want to intervene at home, at school and in other settings, but taking the perspective that not everything needs to be done at once, I would focus my attention on Melissa's parents.

From the description, Melissa's behavior sounds representative of the kinds of behaviors associated with NVLD. Since Melissa's parents are questioning her behavior, it makes me wonder about their understanding of her diagnosis. My role

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could be to help them understand NVLD and how it affects their daughter, their family, their marriage and their life. Ultimately, we could discuss ways of responding to Melissa and managing/coping more effectively at home.

For example, I would start by taking a listening/fact-finding approach. First, I would listen to Melissa's parents (probably on the telephone) and sift through information, such as, "How do you understand Melissa's behavior?" and "What do you know about a NVLD?" I would also want to inquire about what kinds of responses Melissa's parents have tried, "What worked? What did not?" Next, we would schedule an extended consultation. This might be two or three meetings. Again, my approach is to listen and ask questions.

In Melissa's case, my impression is that her parents are searching for answers and support. Given their frustration and their attempts at changing Melissa's behavior, my initial role would be to help them find answers. This is often through trial and error. Understanding the diagnosis is the first step. Responding or developing a plan comes next. The plan might include learning to respond and perhaps anticipate or pre-empt Melissa's behavior, starting at home and perhaps moving to her school. This would involve other family members, teachers and friends. However, keeping the perspective that not everything needs to be done at once, I would initially focus on their concerns and help them understand and cope with Melissa. ■

Watch Us Grow

RNBC Resource Center moves to larger location

Rush Neurobehavioral Center's Resource Center is looking forward to a move this month. Remodeling of a suite on the second floor is near completion. The new space with some added square footage will allow us to have more materials on hand. One goal of the Resource Center is to have multiple copies of the more popular titles. This will enable us to lend materials in the future. A computer will also be installed that will enable visitors both Internet access and the ability to survey new software. There will be a media area to view videos and listen to audiotapes. We have also acquired two new assistive devices, a reading pen for having a particular word read aloud and a watchminder with a vibrating prompt for silent reminders.

The facility can also be utilized for meetings, small lectures, educational programs, inservice programs and other related functions. Extended use of the Resource Center will be available in the near future.

Parent to parent

We are pleased to announce that a parent support group for parents of children with social emotional difficulties is meeting at RNBC. Although the group was initially formed for parents of children with nonverbal learning disabilities, parents with children who have Asperger's and ADHD have been included as well.

Debra Korman, an advisory board member and a parent of an NVLD child is coordinating the group. Each month, a particular area in the family and child's life is the focus of the session. Topics range from the daily "how-tos" that relate to home, family and school to developing friendships and social skills.



Topics have included routines, transitions and how to handle daily homework issues. Each month suggestions made by the group are compiled and distributed at the next meeting so parents can develop their own hands-on manual as an invaluable resource. A recommended book list has also been generated and is continually updated so parents have a place to find information to meet their needs.

The group is meant to be a place for an exchange of ideas among parents, and as a place where professionals in the field of learning disabilities come to offer their expertise to educate parents in an informal and supportive environment.

The group's goal is to provide a safe, supportive and educational setting for parents to learn and exchange information about their children's special needs. Information acquired by parents can ease feelings of isolation and create a happier and healthier family environment.

The group will continue meeting through May, 2000. For more information about joining a support group, call Kate at 847-933-9339, x222.



MASTER PIECE

“The Challenge”

by Kevin Jacobs

“What was the most difficult challenge you have faced in your lifetime and how did you surmount it?” When asked this question for a preparatory high school application, Kevin responded:

The most difficult challenge that I have ever surmounted was coping with my older brother's Nonverbal Learning Disorder. My brother is 16 and he is very smart, just different. I have had a lot of trouble coping and getting along with him at times.

A Nonverbal Learning Disorder is the difficulty to understand communication that doesn't express language directly, but often augments it, including, facial expressions, gestures, body posture, and speaking distance. People with a NVLD can learn, but they learn differently. Having a NVLD, especially for kids, makes it difficult to interact with peers, friends, authority figures, and with family. In order to cope with new situations my brother has a need to control the environment as much as he can. It took me a long time to understand that he just needed to tell everyone what to do so that he knew what to expect.

For instance, my brother has difficulty reading body language, so it is hard for him to see what someone is feeling. It is very frustrating when he doesn't understand what I am trying to tell him with my expressions. The time he is most annoying is when he can't get the signals from me to stop whatever behavior is bothersome. Sometimes, if you make an incredibly mad face at him, it is possible that he might mistake it for another emotion.

Another example of my brother's NVLD problems is that he often is a poor judge of social situations. He will act or speak before he thinks, which has embarrassed me in front of friends. Although I know he means no harm I can get very mad at him. He then feels bad because he doesn't really realize what's wrong. He now understands more, and he asks me to tell him verbally if he is being annoying or inappropriate. This helps him deal with his behavior in social situations.

I was able to surmount the challenge of dealing with my brother by learning more about the disorder. I also learned to be more tolerant and to anticipate my brother's missteps in social situations. I've tried to help him understand more body language, and to be more successful with his peers. I now recognize when he is having trouble and try to help him. My brother may still have his NVLD but I have learned to deal with it, which has brought us closer.

To submit a photo, picture, poem, story or letter for future Newsletter publications, please fax 847-933-4194, email: nbalantz@rush.edu or mail to us at RNBC.



RNBC's 3rd Annual Benefit Dinner honoring Dr. Martha Denckla and Mr. Bill Jacobs

On November 18, 1999, the Chicagoland community came together to support Rush Neurobehavioral Center and honor two very special people. Hinsdale resident Bill Jacobs, civic leader and principal of the Bill Jacobs Automotive Group, received the 1999 Living Proof Award, honoring an individual with neurobehavioral disorders for a lifetime of achievement. Dr. Martha Denckla, renowned behavioral neurologist and professor at Johns Hopkins University, was presented with the 1999 Pearl H. Rieger Award, recognizing her as an individual who has made significant contributions to the understanding of neurobehavioral disorders. More than 400 guests attended the event which raised over \$300,000 in support of the outreach and research missions of the center.

CENTER SPOTLIGHT

Ilene Weil is a learning disabilities specialist and has been with Rush Neurobehavioral Center since July. Ilene has a master's degree in reading and Learning Disabilities from DePaul University. For four years, she was a teacher with the Chicago Public Schools. Last year, Ilene taught at Cove School in Northbrook, a private school for children with learning disabilities.



Ilene currently has two roles at RNBC. She is the coordinator of the Partnership with the Schools Program, a grant funded program designed to help underprivileged students with neurobehavioral disorders experience academic and social success. The goal of the program is to provide special services for a school that doesn't have a special education program in place. The grant focuses on three main areas: diagnostic evaluations, individual teacher support, and teacher education through inservices. The first two inservices covered important topics, behavior management and Attention Deficit Hyperactivity Disorder. Ilene's other role at RNBC is to provide remediation services at the center. In January, Ilene began diagnostic supervision under Pearl Rieger. She feels that being trained by Pearl Rieger is an opportunity of a lifetime.

Meet **Carolyn Lang**, a tireless and deeply valued volunteer of Rush Neurobehavioral Center. Carolyn's involvement at the Center started from her passion for children and education. Aware of the challenges that "differences" create for students and teachers, Carolyn hoped to direct her energies toward making a difference.

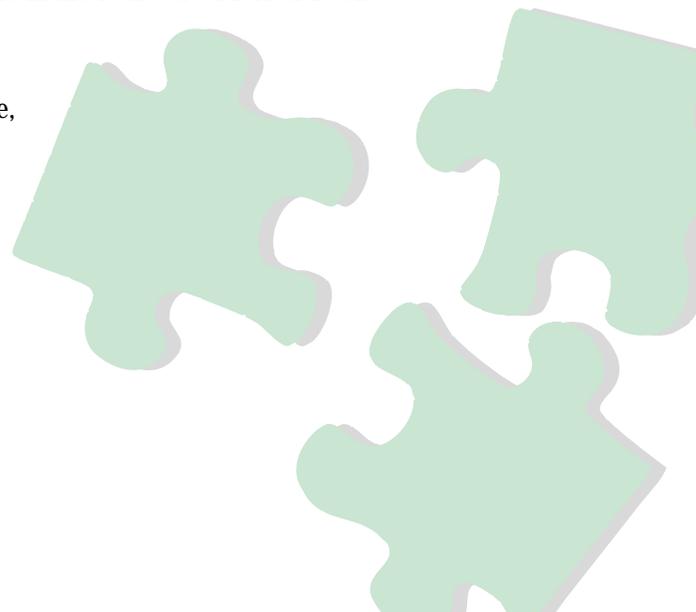


A native of River Forest, Illinois, Carolyn attended Oak Park-River Forest High School and went on to graduate from George Washington University in Washington, D.C. Over the years, Carolyn has dedicated her time and energy to various educational projects. She developed the first voluntary after-school foreign language program for the Parent Teacher Organization in the River Forest School District. She has served as a volunteer for the Parent Teachers Organization, President of the River Forest Board of Education, and serves on the Board of Overseers at the Illinois Institute of Technology's School of Psychology and the President's Council of Dominican University in River Forest.

A member of the RNBC Advisory Board, Carolyn has been responsible for the creation, organization and implementation of the center's educational seminars. Each seminar has focused its attention towards a different audience. "The Child and Adolescent with Neurobehavioral Disorders" by Cathy Oliver was directed towards nurses; "Classroom Interventions for Nonverbal Communications" by Peggy Harlow towards teachers; and "An Afternoon with Martha Denkla and Steven Nowicki" was geared primarily towards parents. In addition to her work developing the seminars, Carolyn has single-handedly cataloged and input all of the information from our vast inventory of books, videos and audio tapes which comprise our library. Her countless hours make real our vision of Rush Neurobehavioral Center's Resource Center.

In Carolyn's spare time, she is owner and president of Silver Creek Bottling Company of Melrose Park. Her vision to partner a wholesome, natural product with a non-profit organization that supports women, has allowed Silver Creek to donate 10% of all profits from its Natural Spring Water brand to the Breast Cancer Fund and the Y-Me National Breast Cancer Awareness Organization.

Carolyn has two sons and currently resides in River Forest with her husband, Henry. Her hard work supports her ongoing mission to fight breast cancer and to make a positive difference for children with neurobehavioral disorders.





We're looking for volunteers to help parents and professionals locate books and articles from our collection, on a variety of neurobehavioral disorders, including ADHD, OCD, autism, etc.

When: hours are flexible

Where: RNBC Resource Center
 9701 Knox Ave., Skokie, Illinois

Contact: Kate Gonley (847) 933-9339, x. 222

"A Celebration of Differences"

narrated by Bill Kurtis

- Honorable Mention in Education
 47th Columbus International Film Festival, 1999
- Honorable Mention, The Sidney Berman Award
 American Academy of Child & Adolescent Psychiatry, 1999
- Favorably reviewed in "Booklist"
 The American Library Association, 1999
- Finalist in Guidance & Counseling
 The New York Festival for Film and Video, 1999



Individuals with learning differences possess unique strengths and gifts. In this film, adults and children describe the strategies and experiences which have enabled them to succeed in a world that often frustrates and confuses them. They discuss their academic struggles, the empowerment that comes from understanding their issues, and the determination that enables them to address life's continuing challenges.

To order: Please make check or money order payable to Rush Neurobehavioral Center. Orders will be processed upon receipt of payment. All sales are final. Tapes may also be purchased at the center.

"A Celebration of Differences" (22 min.)	price	\$ 39.95
	shipping	\$ 5.00
	sales tax	\$ 3.40
	total	\$ 48.35

You are an important piece of our puzzle!

To support the unique programs offered by Rush Neurobehavioral Center, consider a donation. Please include this form with your donation, and mail to: RNBC, 9701 Knox Ave., Suite 102, Skokie, IL 60076

Your donation to our non-profit organization is tax-deductible.

"A Celebration of Differences"
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