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# UPDATE

SOUTH CAROLINA AUTISM SOCIETY

Volume 28

Issue 2

Summer 2000

## Providing a Continuum of Supports

### The 2000 Annual Meeting and Conference

*Sponsored by:*

*Department of Disabilities & Special Needs - Autism Division*

#### **Glen Dunlap, Ph.D.**

editor

*Positive Behavioral Support &  
Journal of Positive Behavior Interventions*

Director,

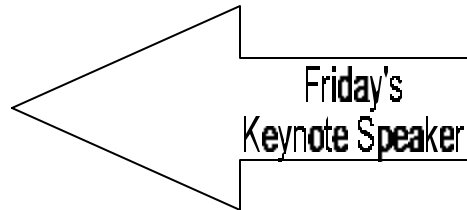
Division of Applied Research and  
Educational Support and

Professor,

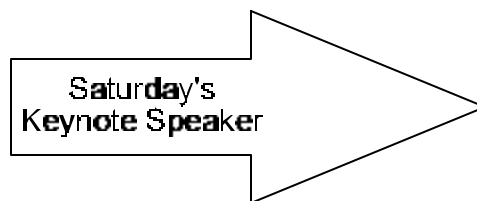
Department of Child and Family Studies &

Department of Special Education

University of South Florida



Friday's  
Keynote Speaker



Saturday's  
Keynote Speaker

Writing Functional and Measurable Outcomes  
The 2nd Annual Pre-Conference Workshop will be held on  
October 5, 2000

Presented by

Dr. Erik Drasgow & Dr. Mitchell Yell

**The Adams Mark Hotel**

**Columbia, SC**

**October 5 - 7, 2000**



Details  
Inside!

# FROM THE DESK OF THE DIRECTOR...

It is once again that time of year when you have the opportunity to nominate someone who has gone above and beyond the call of duty to provide services, support or information about autism this past year. SCAS is currently taking nominations for awards that will be presented at our Annual Meeting on October 7<sup>th</sup>.

If you had a teacher or an aid that worked hard with your child, **you should nominate them**. If you had a service coordinators who helped you work the system to get the services your child needed, **nominate them**. If your autism consultant provided you or your child with that extra support, **nominate them**.

And if you just don't see the appropriate category, make one up. We like to be open to be sure that we are recognizing everyone who has earned it. So be creative. But most importantly, recognize the people who have gone that extra mile to improve the quality of life for individuals with autism in our state.

On page 11, you will find the nomination form. Please fill it out, along with a brief description (150 words or less) of why you feel they desire the award and send it in to the office. Please remember, we must have all nominations in by September 1, 2000.

Thanks  
Craig Stoxen

### PRE-CONFERENCE WORKSHOP

## Writing Functional and Measurable Outcomes

Presented by:

**Dr. Erik Drasgow & Dr. Mitchell Yell,**  
University of South Carolina, College of Education

9:00 am - 3:00 pm (Registration begins at 9:00)

Thursday, October 5, 2000

The Adams Mark Hotel, Columbia, SC

This workshop will focus on writing outcomes for service plans such as the Individual Educational Plans and ????. That are based on developing functional skills and that can be objectively measured. It is an ideal workshop for parents, teachers, service coordinators, facilitators and advocates.

*There is a \$50 registration fee (for non-SCAS members, the fee is \$60) for this workshop.  
It is in addition to the normal conference fees.*

*Please indicate on the registration form if you will be attending!*



# 2000 Board of Directors

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Joyce Nielsen  
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**(2000 - 2003)**  
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(adult son w/autism)

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Visit our website at: [www.scautism.org](http://www.scautism.org)

# 4 Update – Summer 2000

## Autism & Informed Response



**Inclusive Recreational  
Opportunities  
for Adults with Disabilities**

**South Carolina Autism Society  
2000 Award Nomination Form**

Person Making nomination:

Your name \_\_\_\_\_

Address \_\_\_\_\_

City / State / Zip \_\_\_\_\_

Telephone \_\_\_\_\_

Award Categories (check one):

- Sibling Advocate
- Teacher of the Year
- Volunteer of the Year
- Regional Consultant of the Year
- Professional of the Year
- Residential Staff Person of the Year
- Service Coordinator of the Year
- Employer of the Year
- Employee of the Year
- Russell Lee Extra Mile Award
- Other : Special Recognition (You create the award)

Award Nominee's Name \_\_\_\_\_

Address \_\_\_\_\_

City/ State/ Zip \_\_\_\_\_

Telephone \_\_\_\_\_

Is nominee a member of the South Carolina Autism Society ? \_\_\_\_\_

Please print or type on a separate sheet in 150 words or less  
why this nominee deserves special recognition.

**Nominations will not be accepted after September 1, 2000**

**AIR**

When: 1st Floor  
Time: 10:00 AM - 1:00 PM  
Place: Reception  
Contact: Vicki

**ANDERSON**

When: 1st Floor  
Time: 10:00 AM - 1:00 PM  
Place: Reception  
Contact: Vicki

**BALTIMORE**

When: 1st Floor  
Place: Reception  
Contact: Vicki

**CHARLESTON**

When: 1st Floor  
Contact: Vicki

**COLUMBIA**

When: 1st Floor  
Place: Reception  
Contact: Vicki

**FLORENCE**

Contact: Laurie 803-555-0470

**GEORGETOWN**


When: 1st Floor  
Contact: Glenda 803-555-0470

**ORANGEBURG**

Contact: Vicki

**Mission Statement of the South Carolina Autism Society**  
*The purpose of the South Carolina Autism Society is to enable all individuals with autism to reach maximum potential.*

South Carolina Autism Society is a proud participant with United Way.



**The Power of One!**

Please Support your Local United Way.



**FUTURE & SPECIAL NEEDS PLANNING FOR PERSONS WITH A DISABILITY**

*by Barton Y. Stevens, ChLAP*

*This four part series of articles will be of special interest for persons who now have or will have the responsibility of caring for a person with Special Needs. Information is provided so that families will have the knowledge and resources to begin a plan which includes the Letter of Intent, Wills, Special Needs Trust, establishes the Financial need, and addresses Guardianship and Government Benefit issues.*

*The objective is to help families understand the common estate and future planning problems and concerns that face family regardless of the age of the person with Special Needs; to have the basic knowledge and identify resources to help resolve these life planning issues; and to be given viable and affordable resources to take the necessary steps to develop a comprehensive plan that addresses these issues.*

*You will receive information and knowledge which will enable you to know how to make life decisions on behalf of your loved one; prepare a plan with the necessary documents to assure a smooth transition, security, and quality of life while giving you and other family members peace of mind.*

“I’m just praying, praying that she goes a day before I do, then I’ll be able to rest in peace.” said Sarah Firestone, 82, of Wynnewood, Pennsylvania about her 57 year old daughter Phyllis, who has mental and physical disabilities, in an article in the May 1997 *AARP Bulletin* by Susan Crowley titled, “Who Will Care for Paula?” The *Indiana Star* of Fort Wayne, Indiana on November 28, 1993 reported that “an elderly woman and her two adult mentally retarded children were found dead in the family car in what investigators believe was a double murder-suicide.” A neighbor said, “Evidently, she thought no one would take care of her kids.” When these women become the mothers of children with special needs, they didn’t expect them to live past young adulthood, nonetheless to survive them. These tragic circumstances could have been avoided if a plan for the future care of these children had been prepared. It is for this very reason that the question, “Who will care when you are no longer there?” is one that should concern every parent of a child with Special Needs. And, every effort should be made to prepare a plan for the future care and supervision of the person with special needs.

This is the first generation of persons with special needs who will typically survive their parents. Therefore, planning is no longer an option, it is a very significant part of your loved one’s future.

When should a family begin planning? Yesterday! Whether the person with special needs is four or forty years old, it is imperative that families create a plan. A parent never knows when they will no longer be here to care for their loved one. According to the U.S. census of 1991-92, there are now over 10,000,000 persons with developmental disabilities. Less than 20% of these families have done planning.

Families have been told repeatedly at conferences, through support groups, articles, etc. how important it is to plan for their loved one’s future. They understand the importance of preparing a plan. Why then have so few families taken the necessary steps to complete this process? Most families have little free time. Besides taking care of typical family needs, many special needs children require constant care and supervision. Other reasons families give for putting off future planning are; they don’t know how to begin; who to turn to for assistance; concerns about the costs; and it seems too difficult and overwhelming a process.

*Continued on page 8*

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### *Future & Special Needs Planning Continued from page 7*

Each parent should take a moment and think about what will happen tomorrow morning if they are no longer here? Who is qualified to take your place? Do they know what assistance your loved one needs? Are they able to communicate with your child? Do they know the child's daily activity schedule? Who provides the money for the child's care and where is it? How should assets and income be handled so as to avoid the child's SSI and Medicaid benefits being affected? The care providers will have many questions. Who will they ask and how will they get answers if you are not here and have left no instructions? If you don't prepare a plan, who will?

The purpose of these articles is to educate families on the issues needed to be addressed in the planning process, and to provide them with a simple method on how to proceed whether they create a plan on their own or with professional guidance. In addition, options will be provided to enable families to decide which is the best method that makes the process simple and easy to complete.

The planning process addresses four key subjects affecting the life of the person with special needs. They are *Lifestyle*, *Legal*, *Financial Needs*, and *Government Benefits* which will be discussed in Part II.

As families begin their plan they should first identify the people who can assist in the planning process. In addition to family members, it could include, the person with a disability, an attorney, a financial advisor, caseworkers, medical practitioners, teachers, therapists, anyone involved in providing services, and a lifetime assistance planner to act as a "team" advisor to make sure that all parts of the plan are coordinated and complete.

Although families appreciate the value of planning, many are still not sure if they need to prepare a plan today for their loved one. The following questions can help in making the decision. If you answer no to one or more of the following questions, then you should consider reviewing what you have done already or begin immediately.

- *Do you have a written plan to let others know what you want in the future?*
- *Have you asked someone to serve as an advocate or guardian?*
- *Do you understand all of the governmental benefit programs that are available for basic care and supervision?*
- *Have you set aside any additional funds so the person will have a comfortable lifestyle with dignity, self-esteem, and quality of life?*
- *Have you prepared instructions for final arrangements?*
- *Do you have current Wills which excludes your loved one by name?*
- *Does the primary or secondary beneficiaries in your IRA, 401(k), annuities, or life insurance include the person with special needs?*
- *Do you have a properly drafted Special Needs Trust to protect and manage future resources for your loved one?*
- *Has your Special Needs Trust been reviewed by Social Security for compliance?*
- *Have you met with relatives and friends to notify them of your plan?*
- *Have you reviewed your plan in the last year?*
- *Do you feel that you have done everything possible for your loved one's future?*

If you answered no to any or all of these questions, read Parts 2-4 of this series and consider beginning, or adding to your current plan.

**END OF PART ONE – (Watch future editions of SCAS Update for parts 2-4)**

## Research In Autism - by Dr. Ruth K. Abramsom

Research in autism appears to be expanding rapidly for all disciplines. I would like to report on three articles. First, I would like to report on an area which continues to receive a great deal of attention, but does not affect a great many individuals with autism. Kawashima, Mori, Kashiwagi, Takekuma, Hoshika, and Wakefield (2000) in *Dig. Dis. Sci.* recently reported on "Detection and sequencing of measles virus from peripheral mononuclear cells from patients with inflammatory bowel disease and autism. The study examined a small number of individuals with Crohns Disease (n=8), ulcerative colitis (n=3), and children with autistic enterocolitis (n=9). A small "normal" population (n= 8) of health children and patients with lupus and HIV-1 were also examined for the presence of measles RNA in peripheral mononuclear cells. For Crohns Disease, 1/8 patients were positive and had "wild" measles virus characteristics. Measles virus consistent with vaccine strains were found in 1/3 patients with ulcerative colitis and 3/9 patients with autism. The results were consistent with the exposure history of the patients. Thus, in some patients with chronic intestinal inflammation, persistence of measles virus was confirmed in peripheral mononuclear cells. My own personal conclusion from this report is that a subgroup of individuals with intestinal problems show a persistence of measles virus. However, not all of the individuals develop autism. Thus, for the subgroup with autism, there must be additional factors, genetic and environmental, involved which result in the expression of autistic disorder. The issue of vaccines is a difficult one and needs to be carefully researched before broad conclusions are drawn. There may be a *small* subgroup of individuals with autism for whom this is a problem, but probably not the majority of individuals with autism.

Auditory integration training has long been a treatment modality tried for individuals with Autism, with different reported results. Recently, Mudford, Cross, Breen, Cullen, Reeves, Gould, and Douglas (2000) completed a study reported in the *Am. J. Ment. Retard.* 105, entitled "Auditory integration training for children with autism: no behavioral benefits detected." Auditory integration training (AIT) and a control treatment were provided for 16 children with autism in a cross-over double blind study. Measures which included parent and teacher ratings of behavior, direct observational recordings, IQ, language and social/adaptive tests were administered blind to treatment (i.e. treatment vs. control). Parents reported significant differences with the control condition superior on parent rated measures of hyperactivity and on direct observational measures of ear-occlusion. No differences were noted on teacher rated measures. IQ and language comprehension did not increase, but adaptive/social behavioral scores and expressive language quotients decreased. Most parents (56%) were not able to tell retrospectively when their child had received AIT. No individual child was reported as benefitting clinically or educationally. This is a double blind crossover study in which children received treatment. These studies are always hard. This study was carefully completed with both parent and teacher report. The outcome - no benefit on the measures examined - again may reflect a majority, but there may be subgroups for whom the the therapy does work.

Finally, the Collaborative Linkage Study of Autism Group has published the results of "An Autosomal Genomic Screen for Autism" in the *American Journal of Medical Genetics (Neuropsychiatric Genetics 88)*. This study shows findings similar to that of the Duke/USC group with strong linkage on chromosome 7q31-33 and a new finding of possible linkage on chromosome 13.

We are proud that the Duke/USC group has 3 autism research papers accepted for presentation at the International Society for Psychiatric Genetics in Versailles, France, this August. Dr. Harry Wright will be presenting a paper and representing our group along with Dr. John Gilbert from Duke. I will report on these findings after they have been presented. We are still looking for families interested in participating in our research project and are particularly interested in families in which 1 child has autism. We would like to thank everyone for their continuing support. Together, we can make a difference!

I hope everyone has opportunity to attend the ASA meeting in Atlanta. I am sure it will be an exciting and informative meeting, given the fast paced new information which appears every day.

# 2000 Conference Schedule

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Update – Summer 2000

Saturday, October 7, 2000

8:00 - 9:00	Registration	8:00 - 9:00	Registration
9:00 - 9:15	Welcome - Joyce Nielsen, SCAS Board President	9:00 - 9:15	Welcome - Joyce Nielsen, SCAS Board President
9:15 - 11:15	<b>Glen Dunlap, Ph.D.</b> <b>New Directions and Important Perspectives in Positive Behavioral Support</b>	9:15 - 10:15	
11:15 - 11:45	BOOKSTORE	10:15 - 10:45	BREAK - BOOKSTORE
11:45 - 12:00	BREAK - Transition	10:45 - 11:45	
12:00 - 1:00	LUNCH (provided)	11:45 - 12:00	BREAK - Transition
1:00 - 1:15	BREAK - Transition	12:00 - 1:00	Breakout Session #3
1:15 - 2:15	Breakout Session #1 <i>A. Adults with Autism</i> <i>B. Computerized ABA Programs</i> <i>C. Writing Your Own Social Stories</i>		<i>A. Person Centered Planning</i> <i>B. Autism &amp; Informed Response (AIR)</i> <i>C. Estate Planning</i>
2:15 - 2:30	BREAK - Transition	1:00 - 1:15	BREAK - Transition
2:30 - 3:30	Breakout Session #2 <i>A. PECS</i> <i>B. Bio - Medical Panel</i> <i>C. Transition</i>	1:15 - 3:00	LUNCH (provided) ANNUAL MEETING & AWARDS
4:00 - 5:30	Membership Reception		

Friday, October 6, 2000

**THIS IS A TENTATIVE SCHEDULE**

# SCAS 2000 Annual Conference

## REGISTRATION FORM

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

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_

Zip: \_\_\_\_\_ County: \_\_\_\_\_

Phone: (H) \_\_\_\_\_ (W) \_\_\_\_\_

E-Mail: \_\_\_\_\_

\*\*\*\*\*

Are you currently a member of SCAS? Yes No

If no, take this opportunity to join SCAS and save on your registration fees!

**Membership dues are as follows:**

**Individual: \$45 \_\_\_ Family: \$65 \_\_\_ Total Membership \_\_\_**

\*\*\*\*\*

**Registration Fees:**

		Member:	Non Member:	Total:
<b>FAMILY</b>	1 Person	\$ 55.00	\$ 70.00	_____
	2 People	\$ 85.00	\$ 115.00	_____
	Sat. Only	\$ 30.00	\$ 40.00	_____
<b>MEMBER</b>	FT Student	\$ 55.00	\$ 70.00	_____
	Professional	\$ 85.00	\$ 100.00	_____
	3 or more of same grp/each	\$ 80.00	\$ 95.00	_____
<b>PRECONF</b>	Thursday Pre-Conference Workshop	\$ 50.00	\$ 60.00	_____

If you have any special accomendations, call 803-794-2300 by Sept. 25!

Add late fee after September 10, 2000 - \$20.00 \_\_\_\_\_

Enclosed is my:  check  money order **Reg/Mbrshp Total: \$**

Charge my:  Visa  Mastercard \_\_\_\_\_

Name (on card): \_\_\_\_\_

Exp. Date: \_\_\_\_\_

Number: \_\_\_\_\_ - \_\_\_\_\_ - \_\_\_\_\_ - \_\_\_\_\_

Signature: \_\_\_\_\_

**Please fill out one form for each participant!**

Mail to: SCAS, 229 Parson St. 1-A, West Columbia, SC 29169

## SCAS Calendar of Events

### July

- 2-5—ASA Conference - Atlanta, Georgia - call 888-684-4630 for info.
- 4—Independence Day - *SCAS Office Closed*
- 10-14—SCDDSN Training - Applied Treatment Strategies - Coastal
- 17-19—SCDDSN Training - Applied Treatment Strategies - Coastal
- 22—SCAS Board Meeting - Columbia, SC - call 800-438-4790

### August

- 1-3—SCDDSN Training - Basic Treatment Strategies - Charleston
- 11—SCDDSN Training - Introduction to Autism - Midlands
- 16—SCDDSN Training - Introduction to Autism - Pee Dee

### September

- 11-13—SCDDSN Training - Basic Treatment Strategies - Pee Dee
- 12—SCDDSN Training - Introduction to Autism - Coastal
- 19-21—SCDDSN Training - Basic Treatment Strategies - Midlands
- 26—SCDDSN Training - Parent Training - Piedmont

★ **OCTOBER 5-7, 2000 - SCAS ANNUAL MEETING & CONFERENCE** ★

# UPDATE

**Summer 2000**

*South Carolina Autism Society  
Quarterly Newsletter*

Visit us at: [www.scautism.org](http://www.scautism.org)

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**229 Parson Street 1-A**  
**West Columbia, SC 29169-6429**

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COLUMBIA, S.C.

# Update – Summer 2000

## Parent-School Partnership

Program Update—June, 2000

Anjeanette Cheshire - Parent Mentor - Piedmont Region

Another busy IEP season has passed, and the Parent-School-Partnership Program has completed its first year. PSP provided assistance to several families across the state and reported many successes.

Our goal is to provide the tools that will build successful collaborations between parents and schools that assist children with autism reach their maximum potential in the educational system. One important tool is empowerment. The following was taken from Creating a Win-Win IEP for Students with Autism by Beth Fouse, Ph.D.

### ABC's of Parent Empowerment

- A Advocate for yourself and your child.
- B Bring your own “stack of stuff.”
- C Control your anger. Anger begets anger.
- D Develop long-range plans for your child.
- E Educate yourself about autism and your legal rights.
- F Find supports for you and your child.
- G Get involved in your child's educational program.
- H Help other parents cope with the stresses of autism.
- I Initiate IEP meetings or discussions when you have concerns.
- J Jump into the discussion. Don't be intimidated by professionals.
- K Know what you want for your child – work toward those goals.
- L Leave old luggage behind – what happened before shouldn't impact the future.
- M Make lists of concerns, issues, and/or questions – take lists with you.
- N Negotiate – don't form battle lines.
- O Open up and listen to other perspectives.
- P Plan longitudinally for your child.
- Q Question what you don't understand; don't be afraid to speak up.
- R Recognize the realities of the situation.
- S Summarize and restate major decisions of the IEP committee.
- T Treat all parties with respect.
- U Understand that you have a right to express yourself.
- V Visualize your dreams for your child and work toward those dreams.
- W Welcome opportunities for interactions with the school.
- X eXpect the best.
- Y You are the key to a good program.
- Z Zeal can be an asset. Be zealous in your pursuit for a good program.

*Parents need professionals; professionals need parents; and the children need us all.*

Anjeanette Cheshire (Piedmont Region) - e-mail: PSPPIED@scautism.org 864-260-9534

## Membership/Donation Form

The South Carolina Autism Society's *Update* and other activities are made possible through memberships, donations, fundraising and the United Ways of South Carolina. Thank you for your help!

**YES, I want to become a member of SC Autism Society.**

**YES, I want to renew my membership.**

*I understand that my membership in SCAS will include membership in the Autism Society of America.*

Please enroll me for the following membership:

Individual \$45.00     Agency \$400.00

Family \$65.00     Full-time Student \$30

I would like to make a special contribution of \$\_\_\_\_\_.

This donation is made in:  honor of     in memory of

\_\_\_\_\_

Acknowledge to: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

**Payment Options:**

Check/Money Order     Visa     MasterCard

Card #: \_\_\_\_\_ - \_\_\_\_\_ - \_\_\_\_\_ Exp. Date: \_\_\_\_/\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

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

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

Home Phone: (\_\_\_\_) \_\_\_\_\_

Work: (\_\_\_\_) \_\_\_\_\_ Fax: (\_\_\_\_) \_\_\_\_\_

Email: \_\_\_\_\_

**Thank you for your support!**

### South Carolina Autism Society

#### Provides:

- Parent to Parent Network of Support
- Information and Referral Services
- Periodic informational materials and updates
- Regional Support Groups
- Continual involvement in advocacy with governmental agencies and the legislature
- An opportunity to work with people who have common interests and concerns in making a difference for people who have autism
- Annual Conference with workshops and speakers for parents and professionals
- Interagency collaboration

**Autism can  
be treated!**

## Update – Summer 2000

### South Carolina Autism Society New Memberships / Renewals January - June, 2000

Timothy Daughtery	Christy Castor	Mr/Mrs. Bret Marquis
Emile Towler	Mike Smith	Mary Jones Boykin
Frances L. Brannon	Sarah Pascarella	Mr/Mrs. Lovick Fleniken
Mr/Mrs. Don Fender	Bruce Braswell	Mr/Mrs. Donnie Jameson
Carol Weeks	Sidney Coats	Helen Hill
Mr/Mrs. Andrew Nielsen	Selena Yoder	Stu Smith
Alex Holbert	Grace Gifford	Dorothy Tucker
Philip Hazlett	Gloria Sloan	Mr/Mrs. William Bishop
Rev/Mrs. Granville Hicks	Anne Dudek	Barbara Drake
April Rollins	Azilee Proffitt	Risley Linder, Sr.
Judy Beal	Myrtis Rollerson	Gene Grace Holbert
Jack Schoon	Carol Wade	Sarah Harper
Pat McCarthy	Mr/Mrs. James Taylor	Lisa Hyman Lane
Mr/Mrs. Robert McMahon	Mr/Mrs. Charles Banov	Mr/Mrs. Joel Bryant
Mr/Mrs. Henry Daughty	Joy Wilkerson-Bolen	William Floyd
Mr/Mrs. William Walker	Mr/Mrs. Ray Biggs	Mervyn Wagner, PhD
Mrs. Joan Rooney-Graham	Ruth Abramson, PhD	Mrs. Mary Williams
Philip Massey	Ruth G. Bennett	Sharon Coleman

SCAS would not be able to continue assisting families and individuals with autism without your help and support!

**THANK YOU**

### Volunteers and Contributions Needed

More volunteers and community organizations are needed to become involved with **INROAD** in a variety of ways to help provide more opportunities for inclusion.

Please call Kim Pair at 935-5266 for any information needed or assistance you can give or may be able to suggest.

# **Update – Summer 2000**