



# Developmental Disabilities Research Update

Spring 2004

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Autism and  
Developmental  
Disabilities Research  
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## What's New: Collaborations and Conferences!!

By Susan Hepburn, Ph.D.

We are very pleased to announce that research in autism and developmental disabilities continues to grow at the University of Colorado Health Sciences Center. We are very grateful to the families who volunteer their time and contribute significantly to our scientific and clinical understanding of developmental disorders.

Our program of research has expanded into three areas – (1) Developmental, (2) Biological, and (3) Intervention studies. All of the projects are collaborative. Several researchers are working together on various projects – sharing ideas, techniques, and skills. In addition, key members of our research team actively collaborate with community leaders to provide workshops and trainings to parents, pediatricians, educators, and therapists in the Front Range community. The table (on pages 2 and 3) summarizes our current projects and collaborations.

Financially, we are supported by the National Institutes of Child Health and Human Development (NICHD), National Institute of Communication Disorders (NICCD), Cure Autism Now, and the March of Dimes. We are also supported and encouraged by the Mental Retardation and Developmental Disabilities Research Center, the JFK Center, and the Departments of Psychiatry and Pediatrics at the University of Colorado School of Medicine. Due to the decreases in federal funding for disabilities research, we are trying to plan ahead by also conducting some fund-raising activities of our own.

- On June 18<sup>th</sup>, 2004 we will be hosting our first annual Conference entitled **“Linking Research to Practice”**. Presenters from various projects at the University of Colorado will describe their research findings, with a particular emphasis on how this new knowledge can impact education and treatment for children with disabilities. Reservations are necessary and seating is limited – see inside the newsletter for more information! Or call **Galit at 303 315-1253**.

- **We are also set up now to accept donations.** Funds raised will pay for travel costs for families whose children have rare conditions but they live far away, assessment materials, development of training materials, and for laboratory costs (such as videotapes, rewards for the kids, and toys for the kids). If you would like to make a tax-deductible donation to the Autism and Developmental Disabilities Research Group, please contact Cheryl Crouch at the University of Colorado Foundation, 303-315-6917 or Cheryl.Crouch@cufund.colorado.edu.



We are collaborating with the Autism Society of Colorado to collect resource information. If you have any recommendations to include in the directory please send them to ASA Colorado or call Helga Simons at 303-458-6876 or [HelgaSimons4@aol.com](mailto:HelgaSimons4@aol.com)

## Current Projects of the Autism Research Group and Collaborators (Spring 2004)

Project Name and Lead Investigators	Focus of study	Who is eligible?	Contact information
<b>Longitudinal study of development</b>  Susan Hepburn, Ph.D.	Examine development from early to middle childhood in children with various disabilities in order to identify (1) core deficits in specific disabilities; (2) how conditions develop over time, (3) what families might expect as their children grow older, and (4) important targets of intervention	8-11 year olds with autism or fragile X syndrome or Down syndrome or developmental delay; we also need 6-year old typically-developing children	Galit Mankin 303 315-1253  Galit.Mankin@uchsc.edu
<b>Development in Williams syndrome</b>  Susan Hepburn, Ph.D. Deborah Fidler, Ph.D.	Investigate how young children with Williams syndrome: (1) develop strengths in language and social functioning, (2) develop problems with anxiety and attention	2-5 year olds with Williams syndrome and other developmental disabilities	Galit Mankin 303 315-1253  Galit.Mankin@uchsc.edu
<b>Cognitive strengths and challenges in children with Down syndrome and other developmental disabilities</b> Deborah Fidler, Ph.D.	To explore areas of relative strength and weakness in learning styles in children with Down syndrome and other developmental disabilities	Children with Down syndrome; children with idiopathic developmental disabilities; children with fragile X syndrome; other developmental delays	Deborah Fidler 970-491-7870  Deborah.Fidler@colostate.edu
<b>Parent-child interactions, stress, and coping in families</b>  Deborah Fidler, Ph.D.	To explore predictors of stress and resilience in families of children with developmental disabilities	Families of children with any type of developmental disability	Deborah Fidler 970-491-7870  Deborah.Fidler@colostate.edu
<b>Problem-solving in autism</b>  Ben Yerys, MS & Susan Hepburn, Ph.D.	To examine how children with autism solve problems that require them to think flexibly	5-8 year olds with high functioning autism; 4-6 year old typically-developing children	Ben Yerys 303 315-1748  byerys@nova.psy.du.edu
<b>Body Schemas in Adults with Autism</b>  Catherine Reed, Ph.D. Danielle Pulham	To investigate perceptual processes that may impact social functioning in adults with autism	Adults (18+) with autism	Danielle Pulham 303 917-3527
<b>Diet and GI symptoms</b>  Ann Reynolds, MD	To investigate the stomach and bowel problems often reported by parents of children with disabilities	3-7 year olds with autism, fragile X, or other developmental delay	Liz Eno 303 315-1748  Elizabeth.eno@uchsc.edu



## A SPECIAL THANKS!

The Autism Research Group would like to thank Dr. Corry Robinson for allowing our team members to further their educational development. We have been given the opportunity to participate in the following courses: Key Concepts in Developmental disabilities, Leadership Dialogues, and a Practicum in Developmental Disabilities. These classes have been a wonderful experience and we really appreciate her generosity!

<b>Genetics of autism</b> Susan Hepburn, Ph.D.	To gather genetic information for a nationwide study that is investigating possible genetic markers for autism; special emphasis on auto-immune and hormonal functioning	Any individual with autism and their parents	Galit Mankin 303 315-6491  Galit.Mankin@uchsc.edu
<b>Brain Structure and Language Functioning in Parents</b> Don Rojas, Ph.D. Susan Hepburn, Ph.D.	To examine the associations between brain functions with their underlying structures in parents of children with autism	Any individual with autism and their parents	Erin Winterrowd 303 315-5459
<b>Sensory reactivity</b> Lucy Miller, Ph.D. Susan Hepburn, Ph.D.	To use objective, neurophysiological assessments to examine whether children with autism react to sensory events	5-11 year olds with autism	Liz Eno 303 315-1748  Elizabeth.Eno@uchsc.edu
<b>Cognitive-behavioral treatment of anxiety</b> Judy Reaven, Ph.D. Susan Hepburn, Ph.D.	To develop a group therapy treatment model for reducing anxiety symptoms in children on the autism spectrum	7-15 year olds with autism spectrum disorders with average or above intellectual functioning	Galit Mankin 303 315-1253
<b>Teaching nonverbal children with autism useful speech</b> Sally Rogers, Ph.D. Susan Hepburn, Ph.D. Terry Hall, CCC-SLP Renee Charlifue-Smith, CCC-SLP	To compare two methods for teaching speech to young, nonverbal children with autism	3-7 year olds with autism who are using less than 5 words per day	Terry Hall 303 315-6504 Terry.Hall@uchsc.edu

## Significant Findings so far...

### All disabilities

Temperament and problem behavior in children with developmental disabilities – We submitted three articles (Hepburn et al.) concerning how to use information about a child's temperament at age 2-3 to predict problem behaviors around the age of school entry. Our data suggest that we can predict children who are at risk for anxiety symptoms and conduct problems (aggression, tantrums) by examining their response to new experiences and ability to adapt to changes at the age of 2. *Future directions* - We are hoping this research will lead to some ideas about how to help parents of children with difficult temperaments early in life, thus, hopefully, preventing the development of significant problem behaviors by the time they get to school.

Parent reports of sensory functioning: We published an article in the *Journal of Autism and Developmental Disorders* (Rogers & Hepburn, 2003) outlining our findings in a group comparison study of sensory reactivity. Over one hundred parents of children with autism, fragile X syndrome, other developmental disabilities, and typical development participated. We found that children with fragile X syndrome are reported to be most affected by sensory issues, and were particularly challenged by tactile sensitivity, seeking stimulation, poor auditory filtering, and low muscle tone. Children with autism were also



## The Autism Society of Colorado presents: AUTISM ANSWERS

Autism Answers is a 45-minute presentation held at noon on (most) Wednesday's at ASC's office near Washington Park in Denver. Lunch is provided. Autism Answers is designed to provide the general public with answers to some of the more frequently asked questions about autism and the Autism Society of Colorado. They will also take the presentation on-the-road to schools, church groups- anywhere there are people who want to know about autism.

Call ASC at (720) 214-0794 or email at [asc.autismcolorado.org](mailto:asc.autismcolorado.org) for more information or to reserve your spot.

significantly more affected by sensory issues than children with other developmental disorders and had particularly unusual responses to taste/smell and auditory filtering. Unusual sensory responses were noted in children with autism and fragile X regardless of IQ. Unusual sensory responses were associated with problems in adaptive skills, such as socialization, communication, and daily living.

## Autism

Regression and the MMR Vaccine – Our group was involved in the completion of the largest nationwide study of regression and vaccines in children with autism (Richler, et al., 2004). There were 351 children included in the study and the paper is currently under review. The findings suggest that most children who lost skills, such as speech and or motor skills, lost them before the age of three years. The children with a history of language loss had poorer outcomes in terms of IQ and social skills, had a later onset than other children, and had more gastrointestinal symptoms than children without autism who did not experience a loss. While this study does suggest that children who lose speech before they are 3 years old do seem to constitute a separate subgroup of children, there was no evidence that the losses the children experienced were related to the MMR vaccine.

*Future directions* – we are now collaborating with Sally Ozonoff, Ph.D. at the M.I.N.D. Institute to collect and code videotapes of infants who later show symptoms of autism. We are particularly interested in viewing tapes of children who experienced a loss of speech or motor skills. If you are already enrolled in one of our studies and would like to allow us to copy tapes from your child's first 2 years of life, please contact Galit Mankin at 303 315-1253. We are not yet approved to review tapes of children we have not already seen, but we will keep you posted...

Update on Sensory Reactivity – We collaborated with Lucy Miller to write an article on sensory issues in autism for the Winter issue of Autism/Asperger's Digest (Miller & Hepburn, 2004). Our main points were: (1) many children with autism do show either hyper- or hypo- arousal in certain situations, (2) the technology to detect these differences needs scientific attention. *Future directions* - We plan to study whether early differences in sensory reactivity are associated with the development of anxiety disorders in children on the autism spectrum. Dr. Miller is studying psychophysiological methods of measuring reactivity.

Update on Communication Intervention – We also collaborated with Deborah Hayden to write another article for the digest (Hall et al., 2003) that describes the Denver Model and the Prompt approach to communication intervention. We are in the process of writing 2 papers on the effectiveness of each intervention and are analyzing the data now. Of the 21 nonverbal children with autism who completed the study, 18 of them are currently producing words. We need to examine the data carefully to see if we can attribute those gains to the interventions, to growing up, to other interventions or some combination of those factors, but the results are very encouraging! *Future directions* - We have submitted another grant for 5 more years of funding for the speech intervention study.

Emotional responsivity: We submitted a paper with Doug Scambler, Sally Rogers, and others to *Development and Psychopathology* which is being reviewed. We found that young children with autism (ages 2-3 years) demonstrated significantly less sharing of emotional expressions than children with other developmental disorders and typically developing children. Children with autism also showed more muted facial expressions and were less likely to "catch" the emotion of the adult in several different tasks of emotion sharing. We outline a theory that suggests that early emotional functioning may be a core deficit in autism, suggesting specific brain regions (such as the limbic system) that may be involved and calling for specific interventions, such as focusing on teaching children to share emotion early.

## RESOURCES

### COLORADO

*Adams Camp- Special Needs; therapeutic recreation*  
<http://adamscamp.org/>

*Autism Society of Boulder*  
<http://www.orgsites.com/co/asbc>

*Autism Society of Colorado*  
<http://autismcolorado.org>

*Colorado Department of Education*  
<http://www.cde.state.co.us/cdesped/index.htm>

*Colorado Developmental Disabilities Council- Advocacy/Public Policy*  
[cddpc.email@state.co.us](mailto:cddpc.email@state.co.us)

*Denver Options- Denver County Community Center Board*  
<http://www.denveroptions.org/>

*Developmental Pathways*  
<http://www.developmentalpathways.org/>

*Empower Colorado- Support, education & advocacy*  
<http://www.empowercolorado.com/>

*JFK Partners- Child Development Center*  
<http://www.jfkpartners.org/>

*M.A.S.K.- Mothers with Asperger's Syndrome Kids*  
<http://hometown.aol.com/maskas99/mask.htm>

Early social behaviors: We are writing a paper with Bruce Pennington and Sally Rogers about which early social behaviors that we observe in 2-year old children are most important for outcomes 2 years later. So far, young children with autism who demonstrate more emotion sharing with parents and other adults at age 2 have better social skills and less severe symptoms of autism at age 4-5. *Future directions* – we plan to investigate the predictors of language in 4-5 year olds with autism.

Pretend Play – Melissa Rutherford and Sally Rogers published a paper on pretend play in autism and found that these difficulties were related to social understanding (called “theory of mind”) more than attentional issues (referred to as “executive function”). These findings suggest that play in young children may be improved by focusing on social understanding in addition to object play.

Anxiety symptoms in autism – Judy Reaven and Susan Hepburn have collaborated on two papers and two presentations at national conferences concerning the identification and treatment of anxiety symptoms in children on the autism spectrum. Our first pilot group is underway. *Future directions* – we plan to run more groups, make a treatment manual, secure some more grant funding, and study the effectiveness of our intervention in a carefully controlled manner.

## Down Syndrome

Motor planning in Down syndrome – Our group, led by Deborah Fidler, published an article in the *Journal of Occupational Therapy* (Fidler et al., 2004) outlining the specific motor planning problems we observed in young children with Down syndrome. Of particular interest is the observation that children with Down syndrome will use their social strengths to avoid participating in motor challenges, which leads to increasing improvements in social skills and decreasing competence in motor skills. Implications for early intervention are discussed.

## Williams syndrome

Early intervention in Williams syndrome – We are publishing an article in *Infants and Young Children* (Hepburn et al., 2004) that outlines a case study of a 3-year old child with Williams syndrome and describes the implications for early intervention. *Future directions* - We are currently expanding our work in this area and will be writing a grant with Deborah Fidler to pursue a longitudinal study of children with Williams syndrome.

## Fragile X syndrome

Language functioning in fragile X syndrome – We published an article in *American Journal of Mental Retardation* (Philofsky et al., 2004) that describes two different patterns of language development in children with fragile X syndrome. Those who also have autism tend to have more impairments in receptive language than those who do not have autism. Both groups have delays in expressive language. Implications for early identification of children with fragile X who also have autism are discussed. *Future directions* – we plan to examine the development of nonverbal communication in young children with fragile X syndrome.

## RESOURCES

### GENERAL INTEREST

*Autism Society of America*  
<http://www.autism-america.org>

*First Signs- General development information*  
<http://www.firstsigns.org/>

*National Association for Down syndrome*  
<http://www.nads.org/>

*National Fragile X Foundation*  
<http://www.fragilex.org/home.htm>

*National Information Center for Children and Youth with Disabilities (NICHCY)*  
<http://www.nichcy.org/>

*National Institute of Mental Health- Links and Publications*  
<http://www.nimh.nih.gov>

*Williams Syndrome Association*  
<http://www.williams-syndrome.org/>

## Requesting Behaviors in Toddlers with Down Syndrome



By Deborah Fidler, Ph.D. and Amy Philofsky, M.A., CCC-SLP

Recent studies have described that some children with Down syndrome have difficulties with problem solving skills (having a goal, obstacles to that goal, devising strategies for achieving the goal, evaluating the success of those strategies). These studies suggest that children with Down syndrome may also persist less during problem solving tasks than other children with developmental disabilities. They may rely on social strengths, and in particular socially engaging behaviors, to avoid challenging problem solving tasks. This means that some children with Down syndrome may not give themselves the chance to try different strategies to be successful.

How early can this profile be observed in young children with Down syndrome? Can early precursors be identified for this profile observed in older children and young adults with Down syndrome? One candidate behavior is early nonverbal requesting behavior. Requesting behaviors emerge between 9 and 13 months in typically developing infants, at the same time that early problem solving skills emerge. Some have argued that requesting behaviors are closely linked to problem solving, as infants and toddlers are learning that they can “solve the problem” of getting what they need by getting other people to bring it to them. Thus, we may be able to determine whether early problem solving difficulties are already present in toddlers with Down syndrome by observing whether their requesting behaviors have begun to emerge.

Our team analyzed the requesting behaviors of toddlers with Down syndrome, mixed developmental disabilities, and infants and toddlers who were typically developing. We observed these behaviors during play with the experimenter that focused on a series of wind up toys. In most cases, toddlers in this study required help from the experimenter in order to make the wind up toy work. Our study found that toddlers with Down syndrome did significantly fewer requesting behaviors (looking, gesturing, and/or vocalizing to the experimenter) than the children with mixed developmental disabilities and typically developing children in this study. We also found a strong connection between amount of requesting behavior and the ability of children with Down syndrome to complete a problem solving task (reaching through an opening in a box for a prize).

It is interesting to note that other early nonverbal behaviors were very strong in the toddlers with Down syndrome in our study. In particular, toddlers with Down syndrome showed equal amounts of joint attention behaviors (coordinating and sharing their attention with the experimenter), including pointing and looking behaviors. This suggests that overall nonverbal communication is not impaired in Down syndrome, but that these children may have a specific challenge in the area of requesting and problem solving. Our team is working now to generate ideas for how to promote problem solving skills in young children with Down syndrome, or who may have this profile of attenuated problem solving skills.



Here are a few helpful hints to try to get your child to try new foods:

- Serve small food portions and cut food into small bites to fit small mouths. Eating can be a big chore for younger children and a large plate might be a bit overwhelming. It might help to offer your child small portions of something and then let him ask for more
- Do not try forcing your child to eat. Instead, provide regular scheduled meals and snack times
- Make food look more appetizing by including a variety of colors
- Try different ways to prepare the same food. Children may not like the texture of cooked carrots, but may enjoy dipping crunchy raw carrots in to a condiment such as ranch dressing
- When possible let children help prepare the meal. They'll be more likely to eat it
- Let your child feed his or herself. A child who feels confident eating independently will also feel more comfortable eating new things

Continued on page 9...

## Picky Eaters

By Athena Hayes, Project Coordinator, Speech & Language Intervention Study

The broccoli is tossed to the floor. Milk drips off the table. Saucers of spaghetti fly across the room. Your child wants goldfish for lunch. Sound familiar? Difficult eating habits and limited food preferences are among the most distinguishing characteristics of early childhood. Almost a third of children (under age 10) are described by their mothers as picky eaters.

Kids are naturally picky eaters, but given time and your help they can appreciate more diverse tastes. What you serve your children will determine their lifelong eating habits. While parents are responsible for what is offered to their kids, children are responsible for what they decide to eat. Don't be discouraged if your child refuses to eat certain foods. Research shows that the more you serve a food, the more likely your kids are to eat it- even if they don't touch it for a long time. Eating, just like everything else in a child's life, is a learned experience. The more familiar a child is with a certain food, the less likely they are to reject it. Research has also proven that the amount of calories that children eat varies widely from meal to meal, even when two meals consist of the same foods. This means that children have an internally regulated appetite, and healthy children will, over time, eat the amount of food that is right for them.

Remember that eating right isn't all about carrots and broccoli. While you may think that your child's diet is unhealthy, you may be surprised by the amount of healthy vitamin, minerals and protein are in your child's favorite foods. For example, a peanut butter sandwich and a glass of milk will satisfy about half your child's daily grain, protein, and dairy requirements, providing important nutrients (like zinc) as well as essential fatty acids from the peanut butter. A bowl of raisin bran with milk and a glass of orange juice fulfill at least two fruit servings, one dairy, and one grain serving; it also provides fiber, iron, and vitamin C. And a slice of cheese pizza provides almost an entire day's worth of dairy (from the cheese) and a serving of vegetables (from the tomato sauce). As frustrating as your child's picky eating habits may be, keep in mind that you too, may have foods you like and dislike.

### 10 Foods that are a Good Source of Nutrition and Energy for Children

Fresh fruits and vegetables  
Chicken breasts and drumsticks (with or without breading)  
Cheerios, Wheaties, and other whole grain, low sugar cereals  
Skim or 1% milk  
Lean ground beef  
Ice-cream or frozen yogurt (try adding your child's favorite fruit)  
Corn, potato, or fruit chips (apple and sweet potato are yummy)  
Seasoned air popcorn (great mixed with something sweet such as cinnamon)  
Whole wheat or animal crackers

### Suggested Readings

*D.W. the Picky Eater* by Marc Brown

*Coping With a Picky Eater: A Guide for the Perplexed Parent* by William G. Wilkoff

*One Bite Won't Kill You* by Ann Hodgman & Roz Chast

*The Picky Eater: Recipes and Survival Tips for Parents of Fussy Eaters* by Sharon E. McKay

Date: June 18,  
2004

Time: 8am-  
4:30pm

Location:  
Nighthorse  
Campbell  
Auditorium /  
Fitzsimons  
Campus (corner  
of Ursula and E.  
17th PL.)

For further  
information,  
please contact  
Galit Mankin at  
303-315-1253.

Please mail  
registration form  
to:  
UCHSC/Autism  
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## Linking Research to Practice in Autism & Other Developmental Disabilities



The Autism Research Group of the University of Colorado Health Sciences Center and JFK Partners is pleased to invite you to an all-day conference focusing on research-based interventions for children with Autism and other developmental disabilities. The conference features a diverse group of presenters, including professionals from the field of Psychology, Speech & Language, and medicine. Proceeds will support existing research projects in autism at the University of Colorado.

Topics include:

1. Interventions for anxiety symptoms, improving verbal communication, matching educational plans to a child's profile, and promoting appropriate behaviors.
2. Basic research on gastrointestinal symptoms, and sensory reactivity.

Presenters include:

- **Susan Hepburn, Ph.D.** – Principle Investigator of Autism Research Group, Department of Psychiatry, JFK Partners, UCHSC.
- **Judy Reaven, Ph.D.** – Director of the Autism and Developmental Disorders Clinic, JFK Partners, Department of Pediatrics, UCHSC.
- **Amy Philofsky, M.A., CCC-SLP** – Speech-language pathologist. Clinician on the Autism Research Group, Department of Psychiatry, UCHSC.
- **Barbara Brett Green, Ph.D.** – Assistant Professor, Department of Rehabilitation Medicine, STAR Center, The Children's Hospital of Denver
- **Ann Reynolds, M.D.** – Developmental pediatrician for JFK Partners at the Child Development Unit, Department of Pediatrics, The Children's Hospital.
- **Deborah Fidler, Ph.D.** – Educational psychologist, Assistant Professor, Department of Human Development and Family Studies, Colorado State University.
- **Renee Charlifue-Smith, M.A., CCC-SLP** - Director of the Speech-Language Department at JFK Partners, Department of Pediatrics, UCHSC.

Registration Fee: \$75 (Per person)

Unfortunately, we can only accept checks. Please make checks out to UCHSC.

Last Name: \_\_\_\_\_ First Name: \_\_\_\_\_

Phone number: \_\_\_\_\_ Affiliation: Parent / Professional

Breakfast, Lunch (Sandwich, chips and cookie) and refreshments will be provided.

Please select: \_\_\_ Turkey breast \_\_\_ Classic BLT \_\_\_ Tuna \_\_\_ 3-cheese, or \_\_\_  
Vegetarian

Don't Delay – Space is limited!



- Eating and preparing food can be a fun learning experience. Preparing food provides a good opportunity to practice a number of skills-whatever your child's ability: reading (recipes), mathematics (counting, addition, subtraction, fractions), language (labeling foods, identifying features, class, color), and hand-eye coordination (mixing and pouring)

- Offer a multi-vitamin. Remember that vitamins cannot take the place of food, but they can help make up for some nutrients that might be missing from your child's diet. Be sure to consult your child's doctor before deciding to give a multi vitamin.

## Autism and Developmental Disabilities Research Group

Director: Susan Hepburn, Ph.D.

Senior Scientists and Mentors:

Sally Rogers, Ph.D., Bruce Pennington, Ph.D.,  
Sally Ozonoff, Ph.D., Linda Crnic, Ph.D.,  
Corry Robinson, Ph.D.; Randy Ross, MD

Research Collaborators:

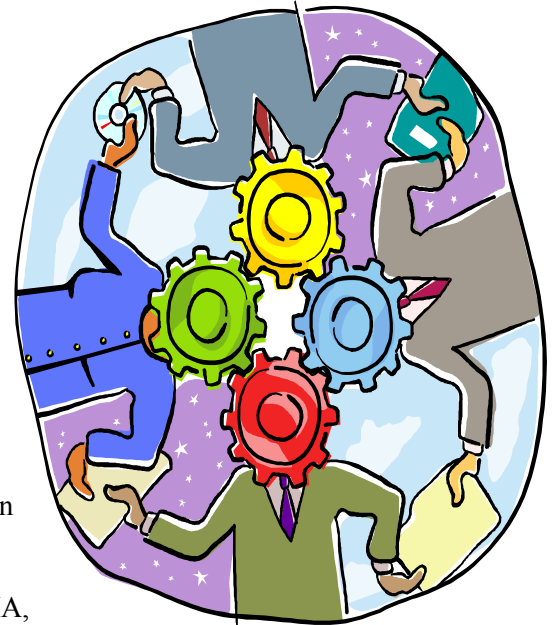
Deborah Fidler, Ph.D., Judy Reaven, Ph.D.,  
Ann Reynolds, MD, Don Rojas, Ph.D.,  
Deborah Hayden, Ph.D., William McMahon,  
MD, Randi Hagerman, MD, Douglas  
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Erin Flanigan , Helga Simons



**We would like to keep in touch with everyone who has participated in our project or who is currently listed in our research database. If you have a new address or phone number, please complete this form and mail it to the address below. Also, if you would like more information on any of the studies described in this newsletter, please return this form and someone from our projects will be happy to contact you. Thank you.**

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

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