

Spring 2006

Volume 7, Number 2



Autism & Other Developmental Disabilities Research Group Newsletter

What's New

By Susan Hepburn, Ph.D.

Evan liked art. He was energized by beauty and responded differently to different artists. He was very visual. And very sensitive. Connecting with him was a special experience.

Evan faced many challenges. Sometimes, he was graceful and zen-like under stress. Other times, he struggled to be understood, and it disorganized him.

Evan passed away in the spring of 2005. In his honor, we are developing Evan's Group, which will be part of the Coping Center for Children with Disabilities at the University of Colorado at Denver Health Sciences Center.

Evan's Group is a new, pilot treatment research program focused on developing good coping abilities in children with developmental disabilities.

The treatment program will have the following elements:

- Family-focused
- Delivered in both individual and group formats
- Open to individuals of all functioning levels and all developmental disabilities.

The intervention services we provide will be part of a research study and, therefore, are experimental and not yet known to be effective with children with disabilities. However, we are modifying strategies that have been demonstrated to work effectively with children who have no known disabilities. Therefore, the intervention program will be grounded in research and conducted in such a way as to enable effective evaluation of program development and intervention outcomes.

Eventually....our work on Evan's Group will lead to the creation of a set of workshops and manuals for use in the community. It is our hope to work with parents, educators, therapists, and physicians on how to promote adaptive coping in a child who faces developmental challenges.

Donations to Evan's group will be utilized to pay for the operation of pilot groups for parents and children with developmental disabilities and coping challenges. Given

the difficulties families face in accessing care, we want to establish Evan's Group to provide free and available mental health care for children with disabilities within a community-based treatment research program.



The program is led by Susan Hepburn, Ph.D., and Judy Reaven, Ph.D., with significant contributions from Shana Nichols, Ph.D., Audrey Blakeley-Smith, Ph.D., Meena Dasari, Ph.D., Joy Browne, Ph.D., Lila Kopelioff, M.S., and Erin Flanigan, B.A. It will be housed at the Department of Psychiatry and the JFK Center, a University Affiliated Center for Excellence in Developmental Disabilities, directed by Corry Robinson.

If you would like to support the development of Evan's Group – Please send donations to: Evan's Group, Autism and Developmental Disabilities Research Group

Or contact Amanda Hastings by email: Amanda.hastings@uchsc.edu, by phone: 303-315-2678, or mail: UCDHSC Department of Psychiatry Autism & other Developmental Disabilities Research Group attn: Amanda Hastings 4200 E. 9th Ave. C268-31 Denver, CO 80262

Inside this issue:

Group Cognitive-Behavioral Therapy	3
Colorado Resource Links	3-5
The Journey through Adolescence	4
Dealing with Social Fears and Worries	5-6
Problem Solving in Down Syndrome	7
Screening for ASD in Schools	8
Overview of Current Projects	9-10

Extreme Makeover of the Group Therapy Room

We are very grateful to Patty, David, and Jeremy Veal for their initiative and creativity in leading an Extreme Makeover of our Group Therapy Room. Jeremy was Project Manager and led a team of volunteers, including Todd Vinson, in the painting and re-decorating project. We are in the process of editing a

videotape of this project, which we are sending to Trading Spaces. We are hoping Genevieve will write to Jeremy to acknowledge his talent and community leadership.

Thank you Jeremy, Todd, Patt, and David for making our treatment space so much brighter!!!



CALLING ALL WRITERS AND ARTISTS!!

We are working on publishing an annual literary/arts journal, entitled: Story Central Station.

We are looking for submissions from children and adolescents to include in this yearly publication, which will be edited by Casey F. Van Sise, a very gifted and creative 5th grade student from the greater Denver area. This project will be Casey's summer

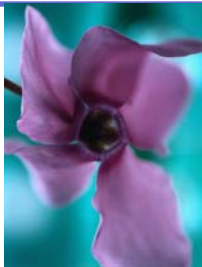
job and we hope to help him compile the journal for publication in the fall. We are looking for:

- Stories
- Poems
- Drawings
- Photographs

Created by children and adolescents who have a unique perspective on the world. Please send your submissions to:

Story Central Station
C/o Susan Hepburn
Department of Psychiatry
4200 E. 9th Ave., Box C-268-30
Denver, CO 80262

Sensory and Behavioral Issues Study



Dr. Robin Gabriels is conducting a study through the University of Colorado at Denver and Health Sciences Center and The Children's Hospital regarding im-

proving the understanding of behavioral and sensory issues in autism spectrum disorders and developmental disabilities in children ages 3 to 18 years. At this time we are specifically interested in recruiting participants of children ages 5 to 12 years. In exchange for complet-

ing several behavioral questionnaires, caregivers will receive a \$10.00 gift certificate for Target. If you are interested in this study or have questions, please contact Dr. Robin Gabriels at (303) 869-3404. Thanks for your interest!

COLORADO RESOURCE LINKS

Adams Camp— Special Needs: therapeutic recreation
www.adamscamp.org

Arc of Colorado – Advocates to help people with developmental disabilities to be full participants in the community
www.thearcofco.org

Autism Society of Boulder—
www.orgsites.com/co/asbc

Autism Society of Colorado—
www.autismcolorado.org

Brain Injury Association of Colorado – Resource directory for TBI survivors and family
www.biaincolorado.org

Colorado Advisory Network – Educational consultation for children with special needs
www.coloradoadvisory.org

Colorado Department of Education— www.cde.state.co.us/

Colorado Fund for People with Disabilities—
www.codisabilitytrust.org/contact/html

Denver Options— Denver County Community Center Board
www.denveroptions.org

Developmental Pathways— Community-based non-profit agency
www.developmentalpathways.org

DisAbility Connection— Resource for families and professionals working with children who have disabilities
www.fortnet.org/DisabilityConnection/

Disabled Resource Services— Resources and Services in Larimer County
www.fortnet.org/drs

Group Cognitive-Behavioral Therapy for Anxiety Symptoms in Children with High-Functioning Autism Spectrum Disorders

By Judy Reaven, Ph.D. & Susan Hepburn, Ph.D.

Children with autism spectrum disorders are at greater risk for developing a variety of anxiety disorders than typically developing children and those with other developmental disabilities. Anxiety symptoms interfere with participation in home, school, and community activities, thus narrowing opportunities for appropriate social engagement. Anxiety also significantly limits family activities, thus contributing to increased isolation for parents and siblings.

Although many researchers and clinicians discuss the significant impact of anxiety on overall functioning of a person with autism, few intervention studies have been conducted. Research on treatment of anxiety in the general pediatric population has demonstrated that cognitive-behavioral interventions are extremely effective in reducing anxiety symptoms in children. “Cognitive-behavioral interventions” refers to strategies that teach children how thoughts (cognitions) are related to emotions and behavior. Teaching children to link experiences in their bodies to their own psychological states is also important with this group of children. Finding ways to support children to cope with their fears, worries, and anxieties instead of resorting to fight or flight reactions when challenged is also an important part of treatment. The present project builds upon previous work in the general population by noted clinical researchers (e.g., Kendall, March) and applies these practices to persons with autism spectrum disorders.

Funding was obtained through the Organization for Autism Research (OAR) and the Doug Flutie Foundation to pilot our intervention package

with families of children with co-occurring anxiety and ASD. The project began in February of 2005 and is nearing completion of the first full year of intervention. To date, our clinical and research teams have written a set of treatment manuals describing a cognitive-behavioral approach for reducing anxiety symptoms in children with HFA or Asperger Syndrome (one for parents, one for children and one for facilitators). We have also completed six full groups (26 families) and expect to have finished two more groups (8 families) by the end of summer. Preliminary analyses thus far indicate that a majority of the children enrolled have experienced a reduction in the severity of their co-morbid anxiety symptoms. Additionally, the parents in our study have reported increases in their own sense of competence in parenting their children.

We have pursued additional funding sources so that we may continue to deliver the group intervention as well as measure the effectiveness of our CBT approach with children who have autism spectrum disorders and co-existing anxiety symptoms. We are also trying to develop interventions for parents of less verbal children. For additional information about this project, you may contact Erin Flanigan at 303-315-1748.

Clinical/Research Teams:

Judy Reaven, Ph.D.
Susan Hepburn, Ph.D.
Shana Nichols, Ph.D.
Audrey Blakeley-Smith, Ph.D.
Joy Browne, Ph.D.
Lila Kopelioff, Doctoral Candidate
Meena Dasari, Ph.D.
Samantha Piper, M.A.
Erin Flanigan, B.A.





The Journey Through Adolescence: Puberty, Sexuality, and Growing Up on the Autism Spectrum

By Shana Nichols, Ph.D., Audrey Blakeley-Smith, Ph.D., Nancy Ratano Lee, M.A. Psychology Post-Doctoral Fellows, JFK Partners

We are pleased to announce continued studies at JFK Partners aimed towards:

1. understanding parents' perceptions, concerns, and service needs related to social skills, sexuality, and growing up in children with an autism spectrum disorder.
2. increasing parents' comfort level in addressing/talking about issues related to puberty, growing up, or their child's developing sexuality.
3. increasing parents' sense of competence in teaching their children about sexuality.
4. reducing stress reported by parents regarding issues related to puberty and growing up.
5. helping parents set goals and teach about issues related to growing up/puberty/sexuality.
6. managing difficult behaviors if they are of concern.

As you know, many children with autism spectrum disorders struggle with social skills such as interacting with peers, making friends and having a conversation. Other skills related to growing up, puberty, relationships and sexuality may also be quite challenging such as:

- understanding physiological changes in the body

- abuse prevention skills (e.g., assertiveness, awareness of strangers)
- managing sexual feelings in a socially appropriate way
- understanding relationships and personal boundaries
- coping with puberty
- sexual health and doctor's visits

Sexuality, Puberty, and Growing Up Parent Course: This 10-week parent course is offered at no cost to families. New groups will begin the week of April 24th and in the summer. Parents of youth with high-functioning autism or Asperger's Disorder ages 11-15 are invited to attend. The program is aimed towards providing parents the skills and knowledge that are important in teaching their children about growing up, puberty, relationships, and sexuality. Contact Kayni Williams for details at (303)-315-6521.

As professionals, we do not know a lot about how youth and adolescents with autism spectrum disorders experience or learn about sexuality and personal safety skills. These studies will allow us to better understand parents' perspectives, concerns, and hopes, and how to best support parents. Our goal is to develop further educational and intervention services for families related to puberty, sexuality, and growing up.

COLORADO RESOURCE LINKS (con't)

Empower Colorado- Support, education & advocacy
www.empowercolorado.com

Family Village – Resources for people with disabilities
www.familyvillage.wisc.edu/index.html

Family Voices of Colorado –
www.familyvoicesco.org

Imagine! –
www.imaginecolorado.org

JFK Partners – Child Development Center www.jfkpartners.org

M.A.S.K. – Mothers with Asperger's Syndrome Kids
www.members.aol.com/maskas99/mask.htm

Mile High Down Syndrome Association –
www.mhdsa.org/

Mile High United Way-
www.unitedwaydenver.org

Pathways Resource Guide – Support and service - located in Aurora, and Arapahoe and Douglas Counties
www.pathwaysresourceguide.org

PEAK Parent Center – Training, information to families and professionals
www.peakparent.org/

Rocky Mountain ADA Information Center- Americans with Disabilities Act
www.adainformation.org/

Roundup Fellowship- Residential, vocational, in-home training and alternative schooling
www.rup.org

Special Education News–
www.specialednews.com

GENERAL INTEREST

Autism Society of America
www.autism-society.org

Autism Networks International
www.ani.autistics.org

Autism Arts
www.autismarts.com

Aspen Center of America -
Autism resources
www.aspenautism.org

First Signs – General develop-
ment information
www.firstsigns.org

FRAXA – Fragile X syndrome
www.fraxa.org

National Association for Down
Syndrome www.nads.org

NADD (National Association of
the Dually Diagnosed)
www.thenadd.org

National Dissemination Center
for Children with Disabilities –
www.nichcy.org

National Institute of Mental
Health www.nimh.nih.gov

Parent Pals –
www.parentpals.com

SERI – (Special Education Re-
sources on the Internet)
www.seriweb.com

Tuberous Sclerosis Alliance –
<http://www.tsalliance.org/>

Williams Syndrome Association
– www.williams-syndrome.org

How to Help Children with Autism Spectrum Disorders Deal with Social Fears and Worries

By Susan Hepburn, Lila Kopelioff, and
Judy Reaven

Many children with ASD struggle with social anxiety – or fears and worries associated with social situations, such as school, parties, and outings of all kinds.

The critical part about anxiety is: **it usually leads to avoidance.** The more we avoid what we are afraid of or nervous about – the stronger those fears and worries become....And the stronger the fears, the greater the avoidance....until the child's world gets very small, often narrowing the worlds of their families as well.

So our job is to support the children to face their fears in small, manageable steps.

Here are some steps that you can take as a parent to help your child combat his/her social fears:

PHASE 1: PREPARATION: (These are the things you do to “get ready” to support your child to cope better with social fears and worries)

1. *Think about your child's specific anxiety symptoms – what does he/she do that lets you know they are feeling fearful or worried? Do you notice any physical signs of anxiety – such as flushing, perspiring, increased pacing or repetitive behaviors?*
2. *Think about the specific social situations that seem difficult for your child.*
3. *Involve your child in communicating with you about his/her fears and worries:*

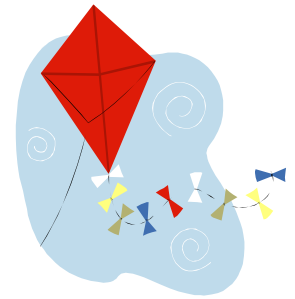
a. If your child is verbal, try to find out about how hard situations are by presenting a series of true/false statements for them to respond to – for example: “I get scared at parties.” This will help you figure out what type of treatment plan might be most beneficial in helping your child. Use visual sup-

ports – such as index cards with “true” and “false” written on them. Practice a few times with statements you know

the answer to -- for example: Doug likes pizza! – You can use “I” statements with highly verbal children (“I like pizza”); however, use the child's name (“Doug likes pizza”) for children with less flexible language.

- b. If your child is less verbal, think about specific social situations where you observe a “fight for flight” response. For example, when does he hide? When does she run away? When does he seem to be more withdrawn?

4. *Try to anticipate social situations that will be challenging for your child.* What's difficult about the social situations that are hard – is it a matter of length of time? Familiarity of the people there? The number of people there? The noise level? What matters about those social situations?
5. *Rank order these experiences by level of difficulty.* This is called “building a hierarchy” – you basically increase difficulty at each step of the ladder. The first step is the easiest. This allows us to support the kids to practice coping in easier situations first, thus increasing difficulty level as the child demonstrates progress coping. There is no “right way” to write a hierarchy – it all depends upon the goals you have for the child. Here's an example for a child who has a difficult time playing with other children, especially unfamiliar ones, and he doesn't like to leave his house and be “out of his element”.



Continued on page 6



How to Help Children with Autism Spectrum Disorders Deal with Social Fears and Worries (con't)

Step 1: 1:1 brief play date with a familiar child in own home

Step 2: 1:1 longer play date with familiar child in own home

Step 3: 1:1 brief play date with unfamiliar child in own home

Step 4: 1:1 longer play date with unfamiliar child in own home

Step 5: brief play date with 2 familiar children in own home

Step 6: longer play date with 2 familiar children in own home

Step 7: brief play date with 2 unfamiliar children in own home

Step 8: longer play date with 2 unfamiliar children in own home

Step 9: 1:1 brief play date with a familiar child outside of home.

As you can see, the steps become increasingly more difficult as you work down the hierarchy. It usually requires several practices before children learn to cope well with each step. Notice that either the length of the activity, the number of children involved, the familiarity of the children involved, and the setting can all be manipulated at each step. Some children need to stay at a step longer than others.

PHASE II: BUILDING COPING SKILLS (These are the tools you will be helping your child to use to cope better.)

1. *Fight back with facts* – Tell your child what you know about their fears....Are there any facts you can share that will help them to see that their fears are not facts? For example, if your child doesn't like to touch things other people have touched due to some fears about germs – then teaching them the facts about germs and our body's immune system can be very helpful.

2. *Remember the fun* – Continually send the message to your child that worrying gets in the way of having fun. Remind them of the activities they enjoy (such as drawing or playing video games) and build in time each day for them to engage in something they really enjoy. If your child doesn't have a hobby, favorite activity or passion, try to find ways to develop one. Occupational therapists can be quite skilled at this.

3. *Move around* – Whether it's walking, jumping, waterplay, bike riding...any kind of sustained exercise activity is very important for supporting active coping.

4. *Breathe* – Changing the way you breathe can really make a difference in how you feel. Try to teach your child to take deep, long breathes that make their bellies fill with air. Breathe in through the nose and out through the mouth. Try to teach them to breathe in slowly and exhale even longer. Practicing these skills in the bathtub or while waiting or driving somewhere can work well

5. *Relax* – Teach your child how her body gets tense and tight when she is nervous and gets more relaxed when she is feeling calm. Practice tensing and relaxing muscle groups in order to learn about these sensations. This will help your child to pay attention to her body and notice that she is feeling scared and worried.

6. *Talk nicely to yourself* – Remind your child of positive statements or he can tell himself: "I can handle this" or "Who cares what happens, as long as I do my best!"). Thoughts lead to feelings and behaviors. Try to give your child a different set of thoughts.

7. *Distract yourself* – Remind your child of what he can think about when he's worried that will calm him – such as naming 3 reasons

why Star Wars III is the best movie ever!; or listing even numbers, or listing state capitals. For less verbal children (and those who are verbal too actually) - provide fidget toys that can be kept in the child's pocket, or attached to his wrist or belt loops.

8. *Provide incentives* – After facing their fears, provide the child with some time to do his favorite thing for quite a while. Saving up particular computer games or solitary play activities as rewards for facing fears can be a good strategy.

PHASE III: PUTTING IT ALL TOGETHER

Beginning at Step 1 (easiest step) of your hierarchy, coach and support your child using the skills described above in order to successfully master each step before moving on to the next step. Your goal is to decrease avoidance and increase engagement.

Social fears and anxieties are real for persons with ASD. As we support the kids in coping, there are also things we can do to create more friendly environments for kids with ASD. In future newsletters we will write about what we can do to create friendly settings for kids with ASD.

Some families include a psychologist in the execution of a coping plan. Many mental health professionals use these techniques, which are called "Cognitive-Behavioral Interventions". Part of our work now is on developing and applying coping interventions for children with autism and other developmental disabilities. If you are interested in participating in our research on anxiety and coping, please contact: Erin Flanigan at erin.flanigan@uchsc.edu or 303 315-1748.



Problem Solving in Young Children with Down Syndrome

By Deborah Fidler, Ph.D.

There is evidence that the earliest years of life for many individuals with Down syndrome involve emerging strengths in social functioning (including strengths in the emergence of nonverbal social communication), and challenges in the development of means-end or strategic thinking (including deficits in the emergence of nonverbal instrumental communication). Dr. Debbie Fidler argues that the cross-domain relations between these two developing areas of functioning contribute to the emergence of a specific personality-motivation orientation, including poorer persistence and an over-reliance on social strategies.

Poorer persistence could be the indirect result of emerging difficulties with instrumental and strategic thinking during infancy in Down syndrome. Toddlers and preschoolers with Down syndrome who quit out of tasks or abandon challenging situations may be doing so because they simply are not able to generate effective strategies to complete the task. That is, they have difficulty coming up with different options that serve as a means to the end of completing the task. Thus, a more passive and less persistent personality-motivation style could be directly linked to emerging primary deficits in instrumental reasoning, and more generally, in cognition.

Furthermore, in those instances when children with Down syndrome are not able to generate new strategies that can serve as a means to an end, it may be that what comes most naturally to them is to recruit their strengths in social skills. As a result, they may develop a style that involves responding to challenging situations with charming or socially engaging behaviors that, ultimately, take them (and their social partner) off task. Or, they may rely on another social strategy, such as recruit-

ing help from a social partner in order to help them complete a task, which has also been demonstrated in several laboratory studies (Fidler, Hepburn, Mankin & Rogers, 2005; Kasari & Freeman, 2001).

In either case, the coupling of poor strategic thinking and strengths in social relatedness is hypothesized to lead to the less persistent and overly social personality-motivational orientation observed in this population. Even in the cases when social strategies are not selected, rather than generating a new strategy for resolving a problem at hand, stubborn behavior suggests that children with Down syndrome get stuck on one particular strategy or approach and can not get “unstuck” from it. If it is true that a less persistent motivational orientation emerges as a secondary phenotypic result of more primary strengths in social functioning and deficits in instrumental (means-end) thinking, it may be possible to alter the developmental trajectory of this personality-motivation profile with targeted and time-sensitive intervention. For example, it may be possible to focus on strengthening early means-end or strategic thinking in very young children with Down syndrome in order to prevent the deceleration of these skills that leads to a split in social and instrumental functioning by the time that intentional communication emerges. Addressing the development of instrumental thinking at this early stage may help to promote a more adaptive personality-motivation style in later early childhood at beyond. At CSU, we have begun to pilot an intervention that aims to build skills in the area of early problem solving (“means-end” thinking).

If you are interested in finding out more information regarding our pilot intervention study, please contact Dr. Deborah Fidler at 970-491-7870, or via email at Deborah.Fidler@colostate.edu.



1. We are 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).
2. We are also accepting donations to Evan's Group. Funds will be used to support the intervention groups focused on improving coping in kids with various developmental disabilities.
3. 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. Please specify “Evans Group” or “General Fund.”

Screening for Autism Spectrum Disorders in Schools



By Kristina
Kaparich, MSPH

Recent data demonstrate that Colorado has the second lowest rate of school-

based identification of autism spectrum disorders in the country. As many of you know, some school districts prefer to identify students under other eligibility categories (such as speech-language or other health impaired.) Therefore, examining school records does not provide a reliable estimate of the number of children who actually have ASD. The focus in Colorado is on matching services to needs; therefore the eligibility category is not thought to drive services. In addition, there is a gap in the technology screening making it more difficult to identify older children who may have ASD. Current screening tools that are available are too time-consuming and expensive to use for all students.

The Colorado Center for Autism and Developmental Disabilities Research and

Epidemiology (CADDRE) developed a quick teacher nomination strategy to screen for high-functioning autism spectrum disorders in elementary school settings. Our goal was to see how reliable and accurate various teacher nomination strategies were compared with a previously validated, more time and resource intensive screening instrument called the Autism Spectrum Screening Questionnaire (ASSQ).

We recruited 60 general education teachers from kindergarten through grade 5 in the Cherry Creek School District, representing 1,355 students at seven schools. Teachers were asked to nominate two students in their classroom who best fit our study-defined description of social and communicative difficulties. Teachers were also asked to complete the ASSQ's 27-item checklist on each child in his/her classroom.

Ninety-five percent of teachers stated that the social and communicative nomination description fit at least one child in the class. The number of students re-

ported to fit the description ranged from 0 to 6, with a mean of 2.5. We found that teachers tended to nominate children who had high ASSQ scores, indicating they are at-risk for autism spectrum disorder. The results of this study suggest that nomination is a promising strategy for identifying children at high-risk for ASD.

We plan to continue reviewing and revising the nomination strategy and to present all the study findings with the Cherry Creek School District. In the spring, Dr. Susan Hepburn will present a series of video conferences to Child Find teams and other educational staff around the state on the topic of screening for autism. These "webinars" are sponsored by the Colorado Department of Education and CADDRE. We have submitted this paper to the *Journal of Autism and Other Developmental Disorders*.

For more information about the School Screening study, please contact Kristina Kaparich by phone (303-315-0066) or by email: Kristina.Kaparich@uchsc.edu.

The Rocky Mountain Clinic for Tuberous Sclerosis

The Tuberous Sclerosis Alliance of the Rocky Mountain Region is proud to announce the creation of The Rocky Mountain Clinic for Tuberous Sclerosis. This multidisciplinary, comprehensive clinic has been established for children birth to 21 affected by TSC. It will allow patients to be seen by necessary subspecialists in a one-day clinic; saving time, emotional strain on patient and family, and money.

The monthly clinic will be held in the Neurology Department at Children's Hospital. It will be a true multidisciplinary clinic, with staff from: Neurology, Neurosurgery, Ophthalmology, Cardiology, Urology, Dermatology, Developmental Pediatrics, Pulmonology, Psychology/Psychiatry, Neuropsychology, and Autism Specialists from the JFK Center.

Tuberous sclerosis complex (TSC) is a genetic condition characterized by lesions of the skin and central nervous system, tumor growth and seizures. Tuberous Sclerosis Complex causes tumors to form in many organs, primarily the brain, heart, kidneys, eyes, lungs, and

skin. Approximately 1 in 6000 live births are affected by TSC, making it as common as Lou Gehrig's disease or Cystic Fibrosis, yet it remains virtually unknown to the general population. Roughly 50,000 individuals in the United States and more than 1 million worldwide have TSC. Tuberous Sclerosis occurs in both sexes and in all races and ethnic groups. Eighty percent of individuals experience seizures and approximately 50% have autistic features. Although TSC is an autosomal dominant genetic disease, two thirds of new cases are a result of a spontaneous mutation. The cause of these mutations is still a mystery.

This clinic will serve patients from an approximate 10 state region. An estimated 2400 individuals affected by TSC will have a place to receive comprehensive, thorough, and experienced care and management of their unique symptoms. Families will receive a continuum of care they would receive nowhere else in the region. The Clinic will turn no one away based on ability to pay for services.

Because of its location, the Clinic will have access to all of Children's Hospital's technology, equipment, and staff; including state of the art brain and kidney imaging, dermatological treatments using the latest laser technology, advanced neurosurgical techniques for epilepsy surgery, and 1,130 pediatric specialists. Research at both the local and national level will be a focus of the clinic and its staff.

A relationship with the national Tuberous Sclerosis Alliance will provide access to research grants, opportunities to network with other TS Alliance approved clinics, the ability to participate in the first-ever national database project for longitudinal research being funded by the NIH, and to further advocacy and support for local families affected with TSC.

If you have any further questions or to schedule an appointment, please contact the Neurology Department at Children's at (303) 861-6895. For more information regarding Tuberous Sclerosis, go to www.tsalliance.org.

Overview of Current Projects of the Autism Research Group and Collaborators

Project Name and Lead Investigator	Focus of Study	Who is eligible?	Contact Information
<p>Longitudinal study of development</p> <p>Susan Hepburn, Ph.D. Amy Philofsky (doctoral candidate) Sally Rogers, Ph.D. Bruce Pennington, Ph.D.</p>	<p>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.</p>	<p>8-11 year olds with autism, fragile X syndrome, Down syndrome, or developmental delay; we also need 6 to 8-year old typically-developing children.</p>	<p>Alison Herndon (303) 315-1253 alison.herndon@uchsc.edu</p>
<p>Development in Williams syndrome</p> <p>Susan Hepburn, Ph.D. Deborah Fidler, Ph.D.</p>	<p>Investigate how young children with Williams syndrome: (1) develop strengths in language and social functioning, (2) develop problems with anxiety and attention.</p>	<p>2-8 year olds with Williams syndrome and other developmental disabilities.</p>	<p>Alison Herndon (303) 315-1253 alison.herndon@uchsc.edu</p>
<p>Cognitive strengths and challenges in children with Down syndrome and other developmental disabilities</p> <p>Deborah Fidler, Ph.D.</p>	<p>To explore areas of relative strength and weakness in learning styles in children with Down syndrome and other developmental disabilities.</p>	<p>2-4 year olds with Down syndrome and children with other developmental disabilities</p>	<p>Deborah Fidler (970) 491-7870 deborah.fidler@colostate.edu</p>
<p>Parent-child interactions, stress, and coping in families</p> <p>Deborah Fidler, Ph.D.</p>	<p>To explore predictors of stress and resilience in families of children with developmental disabilities</p>	<p>Families of children with any type of developmental disability</p>	<p>Deborah Fidler (970) 491-7870 deborah.fidler@colostate.edu</p>
<p>Medical issues</p> <p>Ann Reynolds, MD</p>	<p>To investigate the stomach and bowel problems often reported by parents of children with disabilities</p>	<p>3-5 year olds with fragile X or developmental delay; we also need typically-developing children</p>	<p>Kristina Kaparich (303) 315-0066 kristina.kaparich@uchsc.edu</p>
<p>Leaky gut</p> <p>Ann Reynolds, MD</p>	<p>To evaluate intestinal permeability and gastrointestinal symptoms in children.</p>	<p>Children 2 to 18 years old with Autism or who are typically-developing; with and without GI symptoms</p>	<p>Kristina Kaparich (303) 315-0066 kristina.kaparich@uchsc.edu</p>
<p>Genetics of autism</p> <p>Susan Hepburn, Ph.D</p>	<p>To gather genetic information for a nationwide study that is investigating possible genetic markers for autism; special emphasis on autoimmune and hormonal functioning</p>	<p>Individuals (aged 3 years and older) who have been seen in one of our projects, and their parents and siblings</p>	<p>Kym Gilchrist (303) 315-1780 kym.gilchrist@uchsc.edu</p>
<p>Cognitive-behavioral treatment of anxiety</p> <p>Judy Reaven, Ph.D. Susan Hepburn, Ph.D.</p>	<p>To develop a group therapy treatment model for reducing anxiety symptoms in children on the autism spectrum.</p>	<p>7-14 year olds with autism spectrum disorders with average or above intellectual functioning.</p>	<p>Erin Flanigan (303) 315-1748 erin.flanigan@uchsc.edu</p>

Overview of Current Projects of the Autism Research Group and Collaborators

Project Name and Lead Investigator	Focus of Study	Who is eligible?	Contact Information
Assessment of anxiety symptoms in autism Judy Reaven, Ph.D. Susan Hepburn, Ph.D.	To examine the specific behavior related to mood, attention, and anxiety in children with ASD at all levels of functioning.	7-17 year olds with ASD; regardless of intellectual functioning.	Erin Flanigan (303) 315-1748 erin.flanigan@uchsc.edu
Pragmatics in Williams syndrome and autism Amy Philofsky, M.A., CCC-SLP	To better understand use of a standardized assessment tool for determining pragmatic language impairment in children with developmental disabilities.	Parents of children 6-12 years old with autism, Williams syndrome, or other developmental disability; 5-11 year old typically-developing children.	Amy Philofsky (303)315-7224 amy.philofsky@uchsc.edu
Puberty, sexuality, and growing up on the autism spectrum: A 9 week parent education and skill building group Susan Hepburn, Ph.D.	To evaluate the effectiveness of a group curriculum that provides parent support, education, and skill-building around issues related to puberty, sexuality, and growing up on the autism spectrum	Parents of 11-15 year old children with a diagnosis of autism, asperger's disorder, or PDD-NOS	Kayni Williams 303-315-6521 kayenta.williams@uchsc.edu

Coming Soon (pending approval by the Colorado Institutional Review Board)

Project Name and Lead Investigator	Focus of Study	Who is eligible?	Contact Information
Screening for social, communication, and behavioral issues in Down syndrome Cordelia Robinson, Ph.D. Deborah Fidler, Ph.D. Susan Hepburn, Ph.D.	To screen all children with Down syndrome for social and communicative difficulty in the front range region.	2-8 year olds with Down syndrome; recruitment will be conducted in collaboration with Colorado Department of Public Health	To be announced
Mimicry and imitation in autism and Williams syndrome Daniel McIntosh, Ph.D. Eric Moody, Doctoral Candidate Paula Bealle, Ph.D. Susan Hepburn, Ph.D.	To examine physiological responses to social information across groups with very different social profiles.	7-14 year old children with Williams syndrome or autism	Paula Bealle

Autism Society of Colorado

The Autism Society of Colorado has developed a brief luncheon presentation we call Autism Answers to answer frequently asked questions about autism and the Autism Society of Colorado.

When: Available Upon Request

Where: 701 S. Logan St., Suite 103 . Denver , CO



Who:
Autism
Society of Colorado

What:
Autism
Answers Luncheon

We usually have sandwiches and salad. We begin promptly at noon and end before 1:00pm to honor your time.

When you RSVP, let us know if you have dietary restrictions.

Our office is located on the southwest corner of South Logan and Exposition.

There is plenty of parking in the front and back of the building as well as on the street.

The Autism Society of Colorado's mission is to enhance community awareness and understanding of autism. We have

discovered that the best way to do this is provide a great lunch for a few people at a time in a comfortable atmosphere.

If you would like to invite friends, relatives or business associates to come with you, we would love to have them join you.

Please RSVP by phone or email. We look forward to seeing you.

Autism Society of Colorado

(720)214-0794

www.autismcolorado.org

What's Going On at the Autism Society of Boulder County

ASBC is currently winding down their year, assessing progress of this year's goals and setting new goals for 2006. ASBC's ASD Resource Directory is currently being printed for distribution to parents and professionals to assist in identifying professionals that understand and have a background in treating ASD individuals.

Our free speaker series and support group has begun and meeting information can be found on our website at

www.autismboulder.org.

The recent annual conference, held October 1st, showcased local and national speakers and introduced a biomedical strand to our community and attracted over 300 participants and we are

already planning next year's conference.

Respite is also available and may be applied for on our website.

For more information about ASBC's venues, contact us at 720-272-8231 or visit our website at www.autismboulder.org.

Two New Dr. Partington Workshops in Denver, CO

We would like to share the following information regarding 2 new workshops by Dr. Partington (co-author of the books *Teaching Language to Children with Autism or Other Developmental Disabilities* and *The*

Assessment of Basic Language and Learning Skills) in Denver, CO on April 10th and 11th. For questions, please contact Jamie Hughes at hughes@behavioranalysts.com or (866) 786-6933 ext 703.



Medical Issues in Autism Study

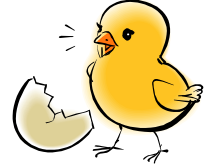
Dr. Ann Reynolds is currently conducting a study of medical issues in children, including gastrointestinal dysfunction, nutrition, and sleep.

This study includes the completion of a three-day diet diary and a seven day stool diary, sleep and family history questionnaire

and a possible lab visit. She is still enrolling children ages 2 to 5 with fragile X, other developmental delays, and typical development.

If you have friends who have children with typical development or developmental delay who might be interested, please

give them our number as comparison groups are very important to the study. If you have any questions please call Kristina Kaparich at 303-315-0066.



Intestinal Permeability "Leaky Gut" Study

Dr. Ann Reynolds is conducting a study of intestinal permeability in children with autism spectrum disorders between the ages of 2 and 18 years of age.

A child does not need to have gastrointestinal symptoms to participate but must be toilet trained.

We are also need children with typical development in the same age range. If you have any questions, please contact Kristina Kaparich at 303-315-0066.

We would like to keep in touch with everyone who has participated in our research projects 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.

Name: _____

Address: _____

Phone number: _____

Email Address: _____

Mail to: Autism and Other Developmental Disorders Research Group
c/o Erin Flanigan
4200 E. 9th Ave., Box C268-30
Denver, CO 80262-0234

Autism & Other
Developmental
Disabilities Research
Group

Department of
Psychiatry

4200 E. 9th Ave.
Box C268-30
Denver, CO 80262

If you have any
questions, please
contact
Alison Herndon at:
(303) 315-1253

University of Colorado at
Denver and Health Sciences
Center

Research Studies Staff

Principal Investigators:

Susan Hepburn, Ph.D.

Sally Rogers, Ph.D.

Bruce Pennington, Ph.D.

Judy Reaven, Ph.D.

Corry Robinson, Ph.D.

Deborah Fidler, Ph.D.

Amy Philofsky, MS, CCC-SLP

Ann Reynolds, Ph.D.

Lucy Miller, Ph.D.

Daniel McIntosh, Ph.D.

Cathy Reed, Ph.D.

Don Rojas, Ph.D.

Barbara Brett-Green, Ph.D.

Shana Nichols, Ph.D.

Research Team:

Alison Herndon, B.A.

Erin Flanigan, B.A.

Kymberly Gilchrist, B.S.

Amanda Hastings, B.S.

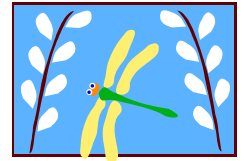
Senior Research Staff:

Kathy Culhane-Shelburne, Ph.D.

Audrey Blakeley-Smith, Ph.D.

*Lila Kopelioff, (doctoral candi-
date)*

Kristina Kaparich, MSPH



We're on the Web!

www.coloradoautismresearch.org



UCDHSC

Department of Psychiatry

Autism & other Developmental Disabilities Research Group

4200 E. 9th Ave. C268-30

Denver, CO 80262

