

**Holiday
OPEN HOUSE**

**MONDAY, DECEMBER 18
4 - 7 PM**

Join the ArcJC staff and board for festive food, live music, and plenty of holiday cheer!

Please RSVP by December 11th to (303) 232-1338 x205 or by email at info@arcjc.org.

The festivities will be held at our offices, located at 8725 W. 14th Ave., Ste 100 in Lakewood.

2007 ArcJC Board of Directors

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Don't miss out on T4T! Sign up now

Space is filling up quickly for the remaining three sessions of Training for Transition (T4T), a weekend seminar for people trying to get a handle on the process of transitioning out of high school.

If your child is in middle school or high school, you may be beginning to wonder what life will look like for your son or daughter when they are out of school. What community supports will be available? What kind of planning needs to be done? Will they live on their own? Will they find a job?

In partnership with Easter Seals Colorado and funded by the Colorado Department of Education, T4T provides an important and unique opportunity to

learn about the issues families face when students in special education begin the process of leaving school for adult life.

Each weekend seminar is designed for participants to gather information, learn about community and government resources, to connect with other families and professionals, and to imagine the possibilities for their child's future.

As one participant said, "I am so grateful for this process. For the first time, I have a very positive and expansive view of the life my daughter can build."

Upcoming sessions include: January 19-21, 2007 at Rocky Mountain Village near Empire, CO; March 2-4, 2007 in Pueblo,

CO, and April 20-22, 2007 at Rocky Mountain Village. A special session with an emphasis on mental health issues will be held March 16-18, 2007 at Rocky Mountain Village.

These intensive weekend seminars start on Friday nights at 5 p.m. and continue through to Sunday at 11:30 a.m. Lodging, meals, and resource notebooks are provided. University credits are available for educators through Colorado State University. Childcare is provided for all sessions conducted at Rocky Mountain Village.

For more information or to register, please contact Easter Seals Colorado at (303) 233-1666 x237.

The Arc in Jefferson County

8725 W. 14th Ave., Ste. 100

Lakewood, CO 80215

(303) 232-1338 phone

(303) 232-9370 fax

www.arcjc.org • info@arcjc.org

INSIDE THIS ISSUE

Critical Resources & News1-3
 From the Executive Director..... 4
 Advocacy Arena5-9

More News..... 9-10
 Get Involved..... 10-11
 Calendar of Events 12

McDonnell Foundation renews Mobilizing support

The Arc in Jefferson County extends our sincere gratitude to the McDonnell Family Foundation for their continued support of our *Mobilizing Families* training program.

Mobilizing Families is designed to equip families of school-aged children with the necessary resources to access support and be the best advocates for their children. Each

8-week session covers a variety of topics to help orient families to the often overwhelming world of parenting a child with a disability.

The McDonnell Family Foundation has been the exclusive supporter of *Mobilizing Families* for the past five years, which has been in existence for fifteen years. Over the years, their generosity has allowed us

to reinstate critical aspects of the program that had been cut due to a lack of funding.

In addition to the two regular sessions conducted each year, starting in 2007, we will now be able to offer three nights of advanced advocacy topics for *Mobilizing* graduates who want to further develop their advocacy expertise.

To read more about the

magic of *Mobilizing Families*, see Jo Lynn Osborne's article on page 5.

The next session begins February 1, 2007. Classes are held on Thursday nights from 6-9 PM. A light dinner and child care are provided. To register, please contact Jo Lynn at (303) 232-1338 x206.

PAD-CO list serve supports parents of adults with disabilities

Parents of Adults with Disabilities in Colorado (PAD-CO) is a list serve for parents of older and adult children.

This informal, non-funded group was started in July of 2002 by parents who wanted a

place where they could confidentially discuss issues related to their older and adult children.

Recent PAD-CO discussions included: The Support Intensity Scale and Tiers Program; Vo-

ational Rehabilitation Services; aging and parenthood; sharing and obtaining specialized equipment; host homes and other positive living arrangements; and sexuality.

Sometimes there is a lot of

discussion, and at times there are only a few posts in a month. No one is ever moderated for their on-topic views or statements.

To join the PAD-CO list serve, email PAD-CO-subscribe@yahogroups.com or contact padcweb@aol.com. Please state that you are the parent or guardian of a child with a disability. For more information, visit www.members.aol.com/padcweb.

Getting Connected

Below is an abbreviated list of agencies and community resources in the Jefferson County area. For additional resources, please visit our Web page at www.arcjc.org.

Access-A-Ride (303) 299-2960: Provides curb-to-curb transportation to passengers who are unable to use RTD buses and qualify for certification under the guidelines established by the Americans with Disabilities Act (ADD) of 1990.

Developmental Disabilities Resource Center (303) 233-3363: Services and resources are provided for people with developmental disabilities in Jefferson, Clear Creek, Gilpin and Summit counties.

Disability Center for Independent Living (303) 320-1345: Centers for Independent Living (CILs) are private, nonprofit corporations that provide services to maximize independence of individuals with disabilities.

Empower Colorado (866) 213-4631: Support, education and advocacy for families of children with mental or emotional health issues, also referred to as brain disorders.

Family First (303) 914-6307: Provides resources to help families obtain respite and child care.

Family Voices (303) 973-5780: National grass roots organization composed of families and friends who care for and about children with special health care needs.

JFK Partners (303) 315-2323: An interdisciplinary program to support people with developmental disabilities at University of Colorado Health Sciences Center. www.jfkpartners.org

Jeffco Action Center (303) 237-7704: Serving homeless people and those at risk of becoming homeless.

Jefferson County Department of Health (303) 232-6301: Provides a variety of services and supports for people with specialized health care needs including WIC and HCP.

Jeffco First Steps (303) 273-1550: To enhance opportunities and support for families of young children with special needs as an integral and valued part of their chosen communities.

The Legal Center for Persons with Disabilities and Older People (303) 722-0300: Protecting the human, civil and legal rights of people with mental and physical disabilities, people with HIV and older people throughout Colorado.

Mental Health Ombudsman Program of Colorado (303) 813-1173: Serves residents enrolled in and receiving mental health services through Medicaid managed care.

Parent to Parent of Colorado (877) 472-7201: Connecting families of sons and daughters with disabilities or special health care needs in communities across Colorado.

ABOUT US

The Arc Independent is a publication of The Arc in Jefferson County, a local unit of The Arc of the United States and The Arc of Colorado.

Todd Lowther • x203
Executive Director

Jo Lynn Osborne • x206
Assistant Executive Director

Patricia Fulton • x202
Educational & Family Advocacy

Corinne Gray • x210
Director of Educational Advocacy

Ann Moulton • x205
Administrative Manager

Louise Todd-Stoll • x207
Director of Individual & Family Advocacy

Jeanne Weis • x204
Director of Adult Advocacy

Genni Williams • x209
Director of Development

Children with Autism waiver begins

More than two years after being signed into law, Colorado's Children with Autism Medicaid Waiver (CWA) program is now official, and services will reach children soon. The CWA program will provide funding to purchase intensive developmental behavior therapies for eligible children ages birth to six who have a medical diagnosis of autism.

Children will be selected from the active Children's HCBS waiver, the Children's Extensive Support waiver, and from children on waiting lists for those programs. Other children will come from the Medicaid program in the SSI disabled category. In all, 75 chil-

dren statewide will receive support through the new Children with Autism Waiver.

Even if they are actively receiving services on another waiver program, children can be on more than one waiver program waiting list at any time. Once a child's name comes to the top of the list, parents can make a decision either to accept or reject the new waiver. If they accept the new waiver program, they give up any existing waiver services. If they reject the new waiver program, they can remain on the existing waiver program. A child can only be active on one waiver program at a time. If parents reject waiver service-

es, the child's name will be removed from the waiting list and families will have to re-apply for a position on the list.

Children with Autism Waiver will use Community Centered Boards as the single point of entry for families. CCBs will conduct an assessment to determine eligibility, and monitor CWA services. Some existing autism service providers will enroll as Medicaid providers for CWA, and it is anticipated that there will be a need to recruit, train, and certify additional providers.

- From Denver Options Fall/Winter 2006 Newsletter

Older American Act Amendments of 2006 re-authorized in Oct.

On October 17th President Bush signed legislation which reauthorizes the Older Americans Act. The Older Americans Act was originally signed into law by President Lyndon B. Johnson. In addition to creating the Administration on Aging, it authorized grants to States for community planning and services programs, as well as for research, demonstration and training projects in the field of aging. The reauthorized Act of 2000 contained an important new program, the National Family Caregiver Support Program, which was designed to help family members who are struggling to care for their older loved ones who are ill or who have disabilities.

Specifically, the Older Americans Act Amendments of 2006:

- o Promotes consumer choice, as well as home and Community based supports to help older individuals avoid institutional care;
- o Strengthens health and nutrition programs while ensuring that no state loses funds to operate these programs;
- o Improves educational and volunteer services;
- o Encourages wealthier seniors to pay for many of their program benefits, maximizing the taxpayer investment for low income seniors;
- o Increases federal, state, and local coordination; and
- o Reforms employment based training for older Americans.

Parents, self advocates, family members and professionals- we are ALL getting older! For more information, call AARP at 1-800-687-2277.

Denver Art Museum to host Access Day Dec. 12

The Denver Art Museum will host a free viewing of the new Frederick C. Hamilton Building for people with special needs and their family and friends on December 12, from 10 am to noon.

Designed by internationally renowned architect Daniel Libeskind, the striking, titanium-clad Hamilton Building is a dynamic environment where visitors can experience art in new ways. The expansion features our outstanding collections of western American art, modern and contemporary

art, Oceanic art, and African art.

Take a guided tour for an overview of the art and architecture, or explore on your own. Wheelchairs, portable stools, and large-print museum guides will be available. Guided tours begin at 10:30 and 11:30 a.m.

For admission, please go to the museum ticket office across from the museum on Martin Plaza. Admission is good for the entire museum complex for the remainder of the day (until 5 PM). For more information, please call (720) 865-4503.

Expert on Down Syndrome coming to Denver in January

The Rocky Mountain Down Syndrome Educational Symposium Series will host a presentation by world-renowned physical therapist Patricia Winders in Denver January 19-20, 2007.

Winders has 25 years of experience working with people with Down Syndrome and is a physical therapy expert at the Kennedy Krieger Institute in Baltimore, MD. She is the author of *Gross Motor Skills in Children with Down Syndrome: A Guide for Parents and Professionals* and has conducted more than 35 Down Syndrome, physical therapy training conferences.

For more information or to register, please contact Mile Hi Down Syndrome Association at (303) 797-1699.

When death comes knocking at your door



by Todd Lowther
Executive Director

My family experienced a devastating death in our family a few weeks ago when my

wife's 82-year-old mother visiting from Florida fell down the stairs in our home. She suffered a traumatic head injury and never regained consciousness, dying at St. Anthony Hospital, where my wife works, the next day—kept alive until the other daughters and grand-daughters could travel across country to be by her side.

In this newsletter and in our trainings for parents we emphasize again and again the need for planning, whether it's individual life planning for someone transitioning from

school to adult life or whether it's end-of-life planning dealing with having a will, advance directives and medical durable power of attorney. Many people avoid the latter, because it's very hard to talk about.

During my wife's sudden loss of her mother, we were consoled by the fact that last summer, during our family's visit to Florida, we had engaged in those difficult discussions. We knew what her mother's wishes were concerning where she wanted to be buried, if she wanted to be kept alive arti-

ficially, and what she hoped would happen with her home and other assets. Of course, during those discussions, we were thinking years into the future, not months.

But because discussions did take place, agonizing decisions, made in emotional distress, were avoided. Believe me, it's tough enough just dealing with the reality of the moment.

By the way, thanks to all of you who have extended your sympathy and support. You cannot know how much it has meant to us.

Trying to break down the language barrier



by Sandy Russalesi, LCSW
ArcJC Board Member & Parent

As a child, my son Danny had no language, yet he could take apart and reassemble the vacuum cleaner. He couldn't tell me what kind of sandwich he wanted, yet he could prepare and bake a cake without instruction after watching me a few times.

We took him to doctors, "experts" who told us he was emotionally disturbed and needed

psychotherapy—not *speech* therapy. Danny was seven years old when we finally got the diagnosis of autism. By then, seven years—years where he could have been getting critical speech therapy—were lost.

Even after his diagnosis, though, there were no available services for my son. In 1969, he couldn't even go to public schools. We joined with other parents and fought hard for mandatory education for people with disabilities. Still, the Individuals with Disabilities Education Act (IDEA) wouldn't be passed for six more years. While we were fighting, Danny had to wait and wait—and wait *some more*—just to go to school.

More time lost.

Verbal communication is one of the most significant components of being human. Without it, the world is very small.

In Danny's world, there is no conversation and no making of small talk. There's no talking about hopes and dreams and no opportunity for griping and complaining. There is also no way to tell someone that you have a toothache.

When frustration, pain and fear cannot be expressed verbally, it often comes out in "unacceptable" behavior. In my experience, almost all behavior problems in people with disabilities are derived from an inability to communicate needs, emotions and desires. These are the people who are not heard and, in many ways, not valued.

As research on Autism has exploded in the last decade, we've learned how crucial early intervention is for children with Autism. Kids now are being diagnosed—accurately—as toddlers. They have access to

a variety of therapies at school and in the community, therapies that drastically increase skills and opportunities for kids with autism.

Danny is now 44-years-old and his inability to communicate continues to be a huge problem for him. We have tried many, many communication tools with him including sign language. So far, nothing has been successful; but fortunately he is still receiving speech therapy. There is some hope that the Picture Exchange Communication System (PECS) and possibly facilitated communication will eventually work for my son.

As his mother, I continue to believe that my son will some day be able to communicate effectively. There has to be a way and I'm going to find it! A mother never gives up.

Families are transformed at Mobilizing



by Jo Lynn Osborne
Assistant Executive Director

Since our last newsletter, we've started and finished another session of our training for families of young children with developmental disabilities, *Mobilizing Families*. Hundreds of families and professionals have attended this training since it started in 1991, yet I never tire of seeing the transformation that happens in our attendees.

The first night of each session is always the hardest. Families come in with equal parts of hope and anxiety, wondering

if this time they will finally get some help and answers. Professionals are simply detached, observing.

To take away any obstacles that might prevent families from attending this crucial training, we provide meals and trained child care. Many of the kids have never been left with non-family or non-school caregivers; their parents are cautious as they drop the kids off with our workers. We assure them their kids will be fed and cared for, and will probably even have a good time, but many of the parents are still cautious.

From there, parents move to our training room and sit down to a relaxing dinner with other adults. For many parents, this is a luxury they have not had for some time. During dinner, parents begin to talk with other attendees, and they start to make connections. As the train-

ing progresses, the connections increase.

One parent states, "I live in the mountains and I don't know anyone else that has a child with autism."

Another parent speaks up and says, "My son has autism and I live in the mountains, where do you live?"

These little connections are crucial. Typically, people come to get information and learn about resources that will help their child; by the end, they've learned more than they could have expected. As one parent said, "I have learned more in this course than I learned in 6 years."

They don't come looking for a sense of community, but they all leave with the connections they've made. By the end of the session, people are arriving early and leaving late, nurturing these new bonds. They come for the training and leave with the seeds of community.

And it's not just the parents who are transformed; some pretty amazing things happen with the children, too. The first night, the kids aren't quite sure of this set up. They are in a new place with new kids and new adults, a place that isn't quite school... they don't know what to make of it.

There are kids of all ages and all abilities, many who haven't had much opportunity to play with peers. This isn't "playing" as a therapeutic or educational tool, it's just good, old-fashioned, raise-a-ruckus playing. Kids interact with the others in their own way, as much or as little as they want. By the end of the session, they've learned how to interact with each other—to play. One little boy liked this toy helicopter with spinning blades. He couldn't pull the switch to make the blades spin, and he couldn't ask someone to

See TRANSFORMATION on page 6

A little planning makes Outdoor Lab a success



by Patricia Fulton
Educational & Family Advocate

Recently, my 12-year-old daughter, who happens to have

a physical disability, attended Outdoor Lab at Windy Peak. She had a fantastic time!

I must admit that I was nervous about how the week would go. I knew the week would be a challenge with all the outdoor activities she would be doing—it's called *outdoor lab* for a reason.

Before her turn at outdoor lab, Kaley and I visited Windy Peak during their open house, which gave us the chance to experience the environment in order to plan for her week.

We discovered there were no paved sidewalks, no railings, no streetlights, and it was very hilly with lots of little rocks.

We looked at each other, doubtful, and said, "Uh-oh, how is this going to work?"

The staff at Windy Peak assured us that Kaley would be able to safely participate in every activity. And she was right. Her teacher scheduled rest periods throughout the day so she would have enough energy to make it through the end of the day, which was nine o'clock at

night or later. For Kaley, being able to stay up until 10 p.m. on a school night was a treat in and of itself.

Her favorite activity was the mountain ecology trail, which was a 1/4 mile hike, where she learned about trees and minerals. Taking a test next to a river beats being in the classroom any day.

Although I had my concerns, with a little advance planning, Outdoor Lab proved to be a great experience for my daughter.

“Tools of the Mind” is step in the right direction



by Corinne Gray
Director of Educational Advocacy

This year, Jefferson County Public Schools implemented a new preschool curriculum that is being used in nearly all preschools district wide. The Tools of the Mind approach helps kids learn self-regulation and choice-making skills. Each day, kids have to make a thoughtful choice – in writing, usually – about what area they want to work in and what their outcome or goal will be for that area. In addition to choosing what they will work on, kids have to stay in the area they choose for a fixed amount of time – no more flitting about from activity to activity or leaving for a different area if they get upset or frustrated. Each Tools of the Mind learning center activity

includes a speech, motor and academic component, so special education needs are able to be supported in the classroom environment.

This curriculum is so cool! I've put three kids through preschool in Jefferson County, and each went to different school and had totally different experiences. This is the first time ever that Jeffco has used a coordinated curriculum for preschool across the entire county. Preschool used to be hit-or-miss depending on the school and the teacher; now it's streamlined across all preschools.

When my oldest daughter went to preschool sixteen years ago, her goal every day was to get married. For three years in preschool she got married every day. I kid you not. It got so out-of-control that the last day of preschool was an organized pretend wedding for her, complete with gown, invitations, flowers, and music. The Tools of the Mind curriculum would not have allowed her to have such marital tunnel-vision every day; she would have had to try other activities.

My second daughter went to preschool fourteen years ago. At

that time, as a child with a disability, her preschool took place in a segregated setting. Her preschool were focused specifically on what she needed individually, not to facilitate group interaction and play. I wanted her to have more peer interaction, so I sent her to a preschool out of district so she could learn group play skills.

By the time my son went to preschool seven years ago, preschool had become more inclusive, and his experience was more like what kids are getting now with Tools of the Mind curriculum. He was in a more

structured preschool program through the Colorado Preschool Project. Like the Tools of the Mind curriculum, this program was designed to focus on helping the child fit within a defined program.

With this new curriculum, the good news is that no matter how any child in Jeffco presents to a preschool, they are going to get a well-rounded, inclusive program that teaches them crucial self-regulation and choice-making skills that will carry them through the rest of their school career.

About Tools of the Mind

Jefferson County Head Start uses the “Tools of the Mind” Vygotskian-based curriculum. The core of the curriculum is based on the ideas about how to amplify development in young children. There are two primary goals:

- To develop underlying cognitive skills, which we define as the development of self-regulation, focused attention, and deliberate memory. These skills are critical for learning and for developing positive self-esteem, and social interactions with others.
- To build the foundation for later academic learning through specific skill development. The specific skills

we focus on have to do with symbolic thinking and the development of early literacy and numeracy. Our program will build these skills through the activity of play and is at the same time developmentally appropriate.

The curriculum is comprehensive, providing the learning experiences in all areas of a child's development including cognitive, language, social, emotional, problem-solving and motor areas. It is also highly individualized, as our educators continually identify the children's needs and abilities, then develop appropriate goals and activities for each child.

~ Jefferson County Head Start web site

TRANSFORMATION from page 5

run the helicopter for him, but each night some child would be sitting there running the plane for him—playing with him.

In this last session, there was one family who felt their son's needs would overburden our child care workers, so one parent always stayed at home with the kids. Because we think it's important to have both parents

attend and get the information, we kept assuring them their kids would be fine, and encouraging them to attend as a family. They finally brought their kids midway through the session. Their son doesn't speak, and he doesn't so much play as move around the room observing what the other kids are doing. We knew he wasn't having

a bad time, but it was hard to know if he liked being there.

On the last night, his dad told the group that as they were on the way to our offices, his son realized where they were going and started to clap. Which is a pretty good indication that he liked being with the other kids.

In just eight weeks, an en-

tire family is transformed, and the transformation is profound, amazing, and inspiring.

Mobilizing Families was designed to meet the needs of the whole family. The next training series will start February 1, 2007. If you haven't attended, this could be your time to experience this amazing transformation.

The rules of citizenship & identity: Are we clear yet?



by Louise Todd-Stoll
Director of Individual
& Family Support

Do you think the rules are clearly spelled out when people are applying for a Colorado license/ ID card and/or public benefits? Have you read—or worse yet, *experienced*—the ongoing banter between our government groups? I understand that policies change, but we have to ensure people know what is expected of them.

Here is some history: Colorado's new anti-illegal immigration laws passed by the legislature this summer set up a strict identification check supposedly meant to "deny most public services to undocumented adult immigrants." As it happens, the Division of Motor Vehicles (DMV) is on the front line of those identification checks, which means the process by which a person obtains a driver's license or identification card has become much more stringent.

At the same time, the federal Deficit Reduction Act of 2005, which was signed into law in February of this year, re-

quires Medicaid clients and applicants to provide documentation to establish both their US citizenship and their identity.

The result? Two pieces of citizenship legislation, one at the federal level and one at the state level, two different sets of rules to establish citizenship.

Also, because of the prevalence of fraudulent birth certificates, the Colorado Department of Revenue (CDR) issued a ruling in September that local and state agencies *would not* accept birth certificates alone as proof of citizenship when a person was seeking public benefits. Instead, a birth certificate can be used in conjunction with another acceptable form of identification, such as a state-issued license or ID. It was the third time in a month the ID requirements were changed.

So why does this matter?

People with developmental disabilities who are lucky enough to receive Medicaid support in the state of Colorado have to re-apply each year. Those who have already been determined eligible could have their services terminated if they fail to provide the appropriate documentation. People newly applying for Medicaid must also provide the appropriate documentation under the federal law.

Under the federal law, appropriate documentation must show proof of citizenship and identification. A U.S. passport, certificate of naturalization, or

certificate of citizenship will meet both citizenship and identification criteria. But most people don't have these documents, so they then have to go to DMV to get a state ID, for which the documentation rules are even more complicated.

In fact, in October federal officials were baffled by Colorado's new edict that even a U.S. passport alone is insufficient proof of identity to get a Colorado driver's license or Colorado ID. To recap: Want Med-

icaid? The feds say a U.S. passport is sufficient. Want a Colorado state ID? That passport isn't going to cut it.

Dutifully trying to produce the proper credentials to maintain their benefits, people with developmental disabilities are being caught in the middle of these confusing and conflicting policies.

But the point is, expectations are continually changing. Will it ever end?

Is it any wonder we are confused?

How to Get Citizenship or Identity Documents

Below is a list of government web sites containing instructions for obtaining some of the required citizenship and identity documents. For the most up-to-date information, contact the agency responsible for issuing the document.

Colorado Driver's License/ID Card

Colorado Department of Revenue

http://www.revenue.state.co.us/MV_dir/wrap.asp?incl=dllist

Colorado birth certificate

Colorado Department of Public Health and Environment:

<http://www.cdphe.state.co.us/hs/certs.asp>

US Passport

US Department of State

http://travel.state.gov/passport/forms/forms_847.html

Certificate of Naturalization (N-550 or N-570) or Certificate of Citizenship (N-560 or N-561)

US Citizenship and Immigration Services

http://www.uscis.gov/graphics/howdoi/replace_cert.htm

Certification of Report of Birth (DS-1350) or Consular Report of Birth Abroad of a Citizen of the United States (FS-240)

US Department of State

http://travel.state.gov/law/info/overseas/overseas_703.html

~ Colorado Health Care and Policy Finance, www.chcpf.state.co.us

E-mail us your feedback or story ideas at info@arcj.org. If you know someone we should feature, contact Genni at 303.232.1338 x209.

People in services need to understand their rights



by Jeanne Weis
Director of Adult Advocacy

Author's Disclaimer: At the time of writing this article, I am temporarily left speechless -- truly without much positive to say. My Mother taught me about not speaking ill of others. So fortunately, I have the opportunity to write about it -- which hopefully doesn't count as actually saying it, right Mom? I truly hope so!

Unfortunately, recently there have been some individuals that I work with that have ap-

plied this concept all too well. There have been several situations of individuals in "abusive situations," for lack of a better term, that are too scared to mention it to the professionals that are monitoring and checking for the safety of these environments.

Perhaps they were silent because of the basic fear of retribution from the provider for speaking up, the fear of losing much needed services, the fear of loss of security, and were living in situations for so long that they believed they deserved the punishment and mistreatment they were receiving. To accept sub-standard living conditions and unethical treatment should not be tolerated. There are rules and protections in place to prevent crimes against at-risk adults, and we all agree

To accept sub-standard living conditions and unethical treatment should not be tolerated. There are rules and protections in place to prevent crimes against at-risk adults. How can we help to drive that message home to the individuals that are being served?

that people in positions of power do not have the right to be abusive.

How can we help to drive that message home to the individuals that are being served?

"The Rights of Individuals Receiving Service" document -- or that same old blue sheet that you "review" at every IP -- is designed to educate and safeguard the rights of individuals, but is apparently too difficult or too complex to understand and apply -- and that makes me sad. What happened to the Golden

Rule -- "Do unto others as you would have them do unto you," and how can we help some providers to understand the concept that people in services deserve to be treated with dignity and respect.

Monitoring and education is the answer, but you simply don't know what you don't know about situations, and often don't see what you don't see. A watched pot never boils. May we all learn and develop additional skills to help explain what rights are, and more importantly--what wrongs are.

What you should know about the abuse of adults with disabilities

Who are the victims?

In Colorado, more than 4,000 incidents of adult abuse, exploitation or neglect are reported each year to local county departments of social services and long-term care ombudsmen. Many more go unreported.

The victims are at-risk adults age 18 or over who due to age or disability are unable to protect themselves and have no one to protect them.

Over 70% are over 60 and are physically impaired or have some form of dementia.

The younger victims are persons with physical or developmental disabilities.

For many, the abuse, exploitation or neglect is caused by a caregiver or a member of their own family. Often the victim is totally dependent upon the abuser, and is afraid to complain for fear of reprisal.

Signs of abuse or neglect

The following are signs that may indicate abuse, exploitation or neglect are occurring:

Physical Abuse

- ◇ Frequent injuries such as bruises, burns, broken bones, especially when the explanation for the cause of the injury does not seem plausible
- ◇ Over medication/sedation
- ◇ Multiple bruises in various

stages of healing, particularly bruises on inner arms or thighs

- ◇ Victim appears frightened or withdrawn.
- ◇ Victim has been locked in a room or tied up

Emotional/Psychological Abuse

- ◇ Sudden dramatic change in victim's behavior: appears withdrawn, depressed
- ◇ Caretaker won't let victim speak for him/herself
- ◇ Caretaker scolds, insults and/or threatens victims
- ◇ Sexual Abuse
- ◇ Evidence of sexually transmitted disease
- ◇ Irritation or injuries to mouth, genitals or anus

- ◇ Victim acts upset when changed or bathed
- ◇ Victim appears fearful when with a particular person

Neglect

- ◇ Filthy living environment
- ◇ Lack of medical attention
- ◇ Lack of dentures, hearing aids, glasses
- ◇ Malnutrition, dehydration
- ◇ Clothing is inadequate for the climate
- ◇ Poor hygiene

Financial Exploitation

- ◇ Unusual activity in bank account; sudden large withdrawals; expenditures that are not

See ABUSE on page 9

ABUSE from page 8

- consistent with victim's past financial history
- ◊ Use of Automated Teller Machines by person who with no history of using ATMs or who cannot access one due to a disability
- ◊ Signing over rights on legal papers without understanding what the papers Mean
- ◊ Eviction for nonpayment of rent; house in foreclosure; utilities shut off, lack of food, clothing or personal supplies
- ◊ Title to home signed over in exchange or promise of "life-long care"

Where to call

- If you are an elderly or disabled adult who is abused, exploited or neglected, or if you know someone who is:
- ◊ Call the police or sheriff, or;
 - ◊ Call the adult protection services unit of your local county department of social services to request an investigation.

County DHS Phone Numbers

- ◊ Clear Creek County DHS Intake: 303-679-2365
- ◊ Gilpin County DHS Intake: 303-582-5444
- ◊ Jefferson County DHS Intake: 303-271-1388

Remember that victims are often unable to ask for help, due to fear or disability. You do not need the victim's consent to make this report.

Under Colorado law, you are protected from liability if you make the report in good faith. You may make an anonymous report.

This information produced by the Colorado Coalition for Elder Rights and Adult Protection www.ccerap.org

Piloting of SIS already making waves

by **Todd Lowther**
Executive Director

Another bomb is exploding in the DD world, one piece of shrapnel at a time around the state of Colorado, in the form of an evaluation called the SIS or Supports Intensity Scale.

This evaluation is being administered hastily on about 500 adults with developmental disabilities in Colorado who receive "comprehensive" services (residential host or group home/day program). The purpose of the 500 being tested by Dec. 15 is to form a pilot group by which rates can be determined state-wide for a particular service paid for by Medicaid. That rate setting will occur after the first of the year and go into effect on July 1. Meanwhile, the rest of those in comprehensive services will be evaluated between January 1 and the end of May— about 3,000 additional people.

The SIS, developed by the American Association for Intellectual and Developmental Disabilities, formerly the AAMR, is touted as an effective planning tool for individuals and claims to give sound, reliable results. It has never, however, been used to develop a rate structure. There are a couple of states, in addition to Colorado, attempting to do that, but no other state has such a short time-frame in which to accomplish the task.

After July 1, all adults receiving Supported Living Services (SLS) will be evaluated using the SIS. The SIS was selected by the state's Division of Developmental Disabilities, in response to Medicaid's directive that the state must have a "uniform, rate-setting methodology." Medicaid had dinged the state for allowing each of the community-centered boards to negotiate their own rates with service providers, a no-no in the Medicaid

world. Although there were other alternatives to the SIS, it came recommended by the same people that have contracted with the state to come up with the new rate mechanism. *Hmmmm.*

To the average observer, the SIS is long and complicated. It takes hours of training in order to be certified to administer the SIS and hours to administer. The answering process is not "user-friendly" and far from "intuitive." A number of parents, some of whom have participated in their son or daughter's evaluation, are posting their reactions on a web site being operated by Parents of Adults with Disabilities in Colorado—PAD-CO. <http://www.members.aol.com/pad-coweb/current.htm> (See article pg. 2)

PAD-CO founder Denver Fox posted the following after attending an informational session on the SIS in late November:

1. The SIS is EXTREMELY complicated and most difficult to understand, especially for folks who have an adult child more involved. It took many questions from the audience to help to understand some of the concepts, and even then, some were not clarified fully.
2. Therefore, I would propose that classes and workshops (from the parents/guardians/child's aspect) be provided to parents and guardians who want assistance seeing that their child gets the fairest evaluation possible. The meaning of the titles and questions is NOT always clear. The more that parents understand the SIS, the more fair the evaluation will be.
3. It was stated that DDD does NOT believe the law requiring permission of guardians/parents prior to an evaluation applies to adults (not minors). This would seem to mean that CCB's will not be required to ask permission of parents/guardians prior to a SIS evaluation.
4. Parents/guardians should consider taking careful notes during an evaluation, especially noting where (if) there are areas of disagreement with the evaluator and the others present in the scoring.
5. Parents should consider getting a copy of the SIS evaluation and results.

The DDD has not yet issued their procedures for appealing the results of a SIS evaluation.

Another parent posted the following after attending his son's evaluation:

My son had his SIS this week. I found it very confusing. One is asked to imagine your child as a "typical" person at whatever age they may be and then to decide what supports he/she would need to accomplish whatever the task is. In addition, the ratings are very confusing ("More than a week but less than once a day", etc.). The respondents may not always agree on what score should be used since they are viewing the person through different lenses. Also, the consumer is asked to make some responses to these complicated areas and may not have a good understanding of what they're being asked to do. For example, if you ask my son if he can cook, he'll say "yes". Well that's true: IF you help him decide WHAT to cook, make a grocery list, take him to the store and help him choose ingredients, back at home help him decide what tools/pans he'll need, and monitor the whole process of chopping, cooking. And his repertoire consists of 2 things he can cook. If his answer were used on the SIS it would not indicate any of the supports he needs. There is a heavily skewed scoring given for behavioral and/or medical issues which is again very confusing.

So, IMHO, the instrument itself may be a good tool but the administration of it is open to a lot of very subjective thinking. Example: my son's host home providers are from a foreign country and see things, and have values, very different from mine. They are also inclined to give a picture that says my son is more competent than he is because they want the agency to value what they are attempting to teach him. I also question whether or not the agency which is going to provide services should be the ones doing the eval. It may be a bit of conflict of interest -- I don't think that is meant to happen but they are being asked to serve lots more people with no more money so they must be able to make it stretch to cover. If this eval is done with none of those constraints, and really looks at the person objectively, it is my belief they will discover there are a lot more needs than are currently identified.

Locally, DDRC has information and links on the SIS at www.ddrcco.com.

The Arc in Jefferson County honors long-time members

It's that time of year where people start counting up their blessings, and we're no exception. The Arc of Jefferson County has been blessed over the years with the steadfast commitment of our long-time members who renew their support for our work, year after year.

A special thanks to all of you who have helped our agency thrive.

35 YEARS

Wayne Whitlock

30 YEARS

Glenn Austin
Jeanne Carney
Else Evans
Leonard & Carole Hemphill
Ed & Diana Hester
Ron & Pat Jurann
Fred & Pat McPeck
Carl & Merry Lou Nuernberger
Byron & Louise Plumley
Robert & Mildred Snow
Larry & Suzanne Widener

20-24 YEARS

John Bateson
Kyle & Gerri Frohne
Mildred Helton
Jerald & Mary Ellen Koehler
Jack Lopez
Barbara Lynch
Clara Murray
JoAnn Stephenson

Raejean Stotler
Frank & Merry Valentin
James & Audrey Wilson

25-29 YEARS

Hugh & Beatrice Adams
Carole Browning
John & Joanne Elliott
William Hall
Arthur & Sydney Hogling
James & Helen Kennedy
Ned & Ellen Koser
Jane Krumm
Vernon & Jeanette Luft
Elizabeth Malonson
Harry & Margaret Porter
Ronald & Verona Skabo
Harriett Wilkinson

15-19 YEARS

William & Kathryn Arrington
Martha Bay
Jo Bellagamba
John & Patricia Brewer
Richard & Laura Burczyk
Ruth M. Cato
Phyllis Dick
Gail Grill
James Hastert
Bernard & Joyce Molley
Alvan E. Morrison
Herman & Patricia Nelson
Jamasp & Katy Oomrigar
Jeanie Osness
Bonita Price
John & Penny Quickle
Deanna Sands
Jerry Shea
Tom & Helen Stroud

William & Rosemary Vetos
Allison Webb
Gene J. & Salome Wiloth

10-14 YEARS

Rosa Lee Ashby
Rachel Baldon
Neil Bradley
Jack & Marilyn Broughton
Ann Cornick
Jeanine Crane
Jerry & Cecilia Duggan
Charles & Cherie Fisk
Joseph & Shirley Geers
Ruth Gerke
Donald & Jeannine Kays
Richard & Ida Knapp
Mike & Linda McGorrin
Pat McPeck
Raymond & Jessica Nowak
Paul Ratz
Lowell Reichert

5-9 YEARS

Elaine & Jenny Angelo
Francisco & Angeliqne Barron
Cathy Bartle
Richard Billings
Pat Bolton
Brian & Lisa Briscoe
Louis & Marilee Bruno
Beth Cole
Donald & Susan Coufal
M.D. & Stephanie Dilworth
William & Dorothy Donovan
Beverly Franklin
Gabriel Gallegos
John & Shirley Gilmore
Betty Goode
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Sarah A. Hartway
Norman & Esther Hicks
Ellie Honeyman
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Mary Jahnke
Stephanie James
Pat Jefferson
Jeffrey Jurann
Joan & Diane Jurann
Ron & Mary Lou Kulbe
Mary LaBate
Dave & Bethany Lidvall
Hannah Lowther
Todd & Paula Lowther
Ron Marquez
Joy Miles
John Ochsner
John O'Dell
Daniel O'Neall
JoLynn Osborne
Sherwood & Marianne Owens
Patrick & Elizabeth Post
Doug & Sherri Potter
Lisa Potter
John & Kathy Ratz
Tim & Sheila Rea
Alan & Patricia Reeves
Shelley Richardson
Jack & Sandy Russalesi
Barbara Rydell
Robert & Camille Sankey
Steven & Cynthia Smetak
Karen Y. Smith
Mike & Sharon Stanley
Dar & Elaine Vriesman
Jeanne Weis
Lori Wightman
Joni Zahller

Arc Independent now accepts advertising

The Arc in Jefferson County is now accepting advertising in our bi-monthly newsletter, *The Arc Independent*. Sizes range from business card size to full page advertising, with prices starting at \$25 for a single business card sized ad. Discounts are available for nonprofits.

Due to USPS bulk mail regulations, we are unable to accept advertising for travel, insurance or credit cards.

To learn more about our advertising options, please contact Genni Williams at (303) 232.1338 x209 or by e-mail at genni@arcjc.org.

The staff and board of The Arc in Jefferson County extends our sincere gratitude for grants received from the McDonnell Family Foundation and the A.V. Hunter Trust to support advocacy programs.

New program dares people to "Think Different"

The Arc in Jefferson County has started a new community awareness program to help spread the word about the work of our organization and the needs of people with developmental disabilities.

This free, one-hour "Think Different" tour is designed to inform our community about the work we do and the ways that advocacy can change the lives of people with

developmental disabilities of all ages. We believe these tours can be a tool to help our community change how they think about ability, and about people with developmental disabilities.

Attendees will hear about the experiences of people with developmental disabilities, learn about the obstacles that still face our community, and learn about

the work we do here to help people with developmental disabilities live full and enriching lives.

Tours are held the first Wednesday of every month, from 12 to 1 p.m. Evening tours are also available. If you are interested in attending our tour, please RSVP to Genni Williams at (303) 232-1338 x209 or by e-mail at genni@arcjc.org.

Membership

NEW MEMBERS

Debbie Fowler
 Sherri Horan & Barry Knott
 Robert & Deborah Johnson
 Marianne Monagle
 Kristin Ringie
 Christopher Romero
 Mike Wittmann

RETURNING MEMBERS

Elaine & Jenny Angelo
 Rosa Lee Ashby
 Francisco & Angélique Barron
 Jo Bellagamba
 Jack & Marilyn Broughton
 Brian & Terry Burbank
 Lynn & Mary Carpenter
 Ann Cornick
 Mary Curtin
 John & Joanne Elliott
 Charles & Cherie Fisk
 Ruth Gerke
 Tamara Goff & Adam Bishop

Corinne & Gene Gray
 Donna Gunnison
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 Ron & Mary Lou Kulbe
 Mary LaBate
 Chip & Angela Langowski
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 Hugh & Laura Marrs
 James & Lisa Martinez
 Kari Mayberry
 Kathy McAdoo
 Glenda Miller
 Marc Morse & Lauren Clark
 Raymond & Jessica Nowak

John O'Dell
 Jo Lynn Osborne
 Jeanne Osnes
 Byron & Louise Plumley
 Lisa Potter
 Doug & Sherri Potter
 Bonita Price
 John & Kathy Ratz
 Shelley Richardson
 High Plains Pediatric Therapy
 Karen Y. Smith
 JoAnn Stephenson
 Kathy Stortz
 David Vincent
 Dar & Elaine Vriesman
 Allison Webb
 Jeanne Weis
 Lori Wightman
 Gene J. & Salome Wiloth
 Bob & Robin Zaborek
 Joni Zahller
 Susan Zimmerman & Paul Phillips

Contributions

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Jack & Marilyn Broughton
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 William Hall
 Sherri Horan & Barry Knott
 Kari Mayberry
 Dar & Elaine Vriesman

SILVER LEVEL

Lynn & Mary Carpenter
 Marcia Hughes & James Terrell
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 Tamara Goff & Adam Bishop
 Ron & Pat Jurann
 Jane Krumm
 Jack Lopez
 Kathy McAdoo
 Marianne Monagle
 John O'Dell
 Jeanne Weis

The ArcJC accepts credit cards

One more way to pay! The Arc in Jefferson County is now able to accept donations by credit or debit card. Simply fill out the form on the next page and mail it in, or visit our secure online donation page (www.arcjc.org > Give > Online Donations) or call us with your information. Donations can be made on a one-time-only basis or can be scheduled in monthly installments.

Support our cause!

Full Name _____

Address _____

City, State, Zip _____

Phone _____

E-mail _____

Annual membership rates: Individual \$15, Family \$19, Individual with developmental disability \$5, Couple with developmental disability \$7

Yes! I want to become a member of The Arc. My dues of _____ are enclosed.

Yes! I want to make a tax-deductible contribution:

by check Amt \$ _____

by credit card Amt \$ _____

Check one: VISA MC DISC

Number: _____

Exp.: _____ Signature _____

Please contact me about stock donations.

Please send your completed form to:

The Arc in Jefferson County
 8725 W. 14th Ave, Ste. 100
 Lakewood, CO 80215

Calendar

December 2006

Tuesday, December 5

Board of Directors Meeting. 6:00 to 8:30 p.m.

Wednesday, December 6

ArcJC Think Different Tour. 12 to 1 p.m.

Rocky Mountain Partners Aktion Club.

ArcJC offices, 4 to 5 p.m.

People First. 6:30 to 8 p.m.

Tuesday, December 12

ArcJC Think Different Tour. 4:45 to 5:45 p.m.

Monday, December 18***

ArcJC Holiday Open House. 4 to 7 p.m.

***Please note the correct date is Dec. 18th.

Please RSVP by 12/11/06. See page 1.

Wednesday, December 20

Rocky Mountain Partners Aktion Club.

ArcJC offices, 4 to 5 p.m.

Thursday, December 21

People First Coffee House. 6:30 to 8 p.m.

Atlanta Bread Company, Alameda & Wadsworth.

December 22-25

ArcJC Offices closed for Christmas holiday.

January 2007

Monday, January 1

ArcJC Offices closed for New Year's Day.

Wednesday, January 3

CANCELLED: *ArcJC Think Different Tour*

Rocky Mountain Partners Aktion Club.

ArcJC offices, 4 to 5 p.m.

People First. 6:30 to 8 p.m.

Monday, January 15

ArcJC Think Different Tour. 4:45 to 5:45 p.m.

Wednesday, January 17

Rocky Mountain Partners Aktion Club.

ArcJC offices, 4 to 5 p.m.

Board of Directors Meeting. 6:00 to 8:30 p.m.

Thursday, January 18

People First Coffee House. 6:30 to 8 p.m.

Atlanta Bread Company, Alameda & Wadsworth.

January 19-21

Training for Transition, Rocky Mountain Village, Empire, CO. See article page 3.

February 2007

Wednesday, February 7

ArcJC Think Different Tour. 12 to 1 p.m.

Rocky Mountain Partners Aktion Club.

ArcJC offices, 4 to 5 p.m.

People First. 6:30 to 8 p.m.

Tuesday, February 13

ArcJC Think Different Tour. 4:45 to 5:45 p.m.

Thursday, February 15

People First Coffee House. 6:30 to 8 p.m.

Atlanta Bread Company, Alameda & Wadsworth.

Monday, February 19

ArcJC Offices closed for President's Day

Wednesday, February 21

Rocky Mountain Partners Aktion Club.

ArcJC offices, 4 to 5 p.m.

Board of Directors Meeting. 6:00 to 8:30 p.m.



The Arc in Jefferson County
8725 W. 14th Ave., Ste. 100
Lakewood, CO 80215
www.arcjc.org

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