

# BETWEEN THE LINES



COLORADO DEVELOPMENTAL DISABILITIES COUNCIL

SPRING 2010

## SAFE?

By *Mama Ares*

My friend tells about the idea he had as a young father that all he wanted for his daughter was to keep her in a room with soft padded walls so that she would always be safe. That idea ceased to reassure him once he realized that his daughter was fine, just the way she was, and that she was a citizen of the world along with the rest of us.

Parents of children with disabilities will probably recognize my friend's impulse, misguided though it was, to keep his daughter safe. Acquiring a label of disability opens up the question of safety in different ways than for any child. When we have young children in our care we look for rounded corners as toddlers begin to learn to walk, we admonish kids to stop and look before crossing a street, to hold our hands or ride in the shopping cart at the store and in the parking lot. Add a wheelchair or the need to figure out alternatives to verbal communication, and the awareness of the need for safety is heightened.

**What constitutes safety? We have phrases like, "Safety in numbers!" and "Better safe than sorry!"**



The two familiar phrases represent both sides of the question. "Better safe than sorry!" often leads people to err on the side of caution. We think of safety in terms of soft corners and protective isolation. That's where safety in numbers comes in. Parents can be convinced that the facility with the latest technology, or the school that has a therapeutic swimming pool, is the safer alternative to the local elementary or high school, or the neighborhood home or apartment. However, being in the specially designed building usually isolates the person with a disability from their peers, from people who Eugene Marcus\* calls "everyday people." Isolation turns out to be unsafe. Where are the other kids, the friends, the neighbors?

Unfortunately, we know that people with disabilities are subjected to abuse and neglect in greater numbers than people without disabilities. The issue has been in the news this year as a bill in Congress alerts us to the widespread use of seclusion and restraint of students with disabilities in our public schools. Those terrible practices occur when students are segregated, away from the view of everyday students and teachers. Since my son is my most poignant reference point when I consider what it's like

to live with disabilities in our society, I know that he is not safe when he's isolated with the person who is supposed to keep him safe. In such situations he has been hurt by people who can inflict harm and be relatively certain that, because he doesn't speak, he will not identify them as the perpetrator.

Safety in numbers allows the everyday person to notice the oddities in practices that are designed with supposed safety as the uppermost consideration. One middle-school student, who had gone to elementary school with my son, was able to speak up and say, "What's up with his aide making him wear that pink and blue leash (gait belt) when he's walking in the hall?" The student knew more about my son's ability to walk, run, and climb stairs, than the school personnel who had just met him. The student also was quick to spot stigmatizing treatment of his friend.

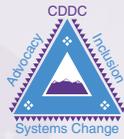
One of my friends tells of growing up in a small town next to a very large state institution for people with disabilities. He noticed that when the people from the institution would show up in town, as a group, they would automatically line up, no matter where they were—in the coffee shop, at the bus stop, in the park. People



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# Sister Act Section



## The Legal Center helps find new homes for residents of Grand Junction Regional Center

By Randy Chapman

The Grand Junction Regional Center (GJRC) has a mission to promote quality of life, safety, and independence for people with developmental disabilities. The center serves people with complex medical and psychiatric needs with the goal of helping each person achieve the highest level of independence possible.

Last August, Governor Ritter announced that because of the state's budget crisis, GJRC's skilled nursing unit would close effective February 28, 2010. For the 32 residents affected by the decision, that unit was their home, raising serious concerns about the impact of the proposed move on their health and wellbeing. These individuals all have significant needs for support; some use wheelchairs, and many cannot talk—although that does not mean they cannot communicate.

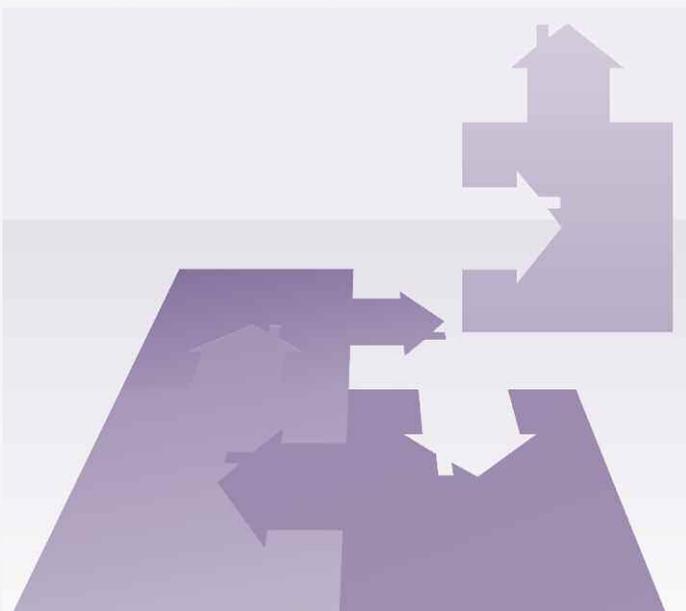
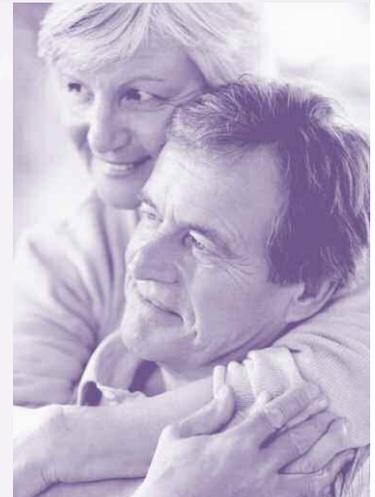
The Legal Center was initially told that the individuals would move to nursing homes, which we have always considered as unacceptable for people with developmental disabilities.

We communicated that to the Colorado Division for Developmental Disabilities, and we also offered to help the residents and their families in transitioning to community settings such as group homes, host homes, or personal care alternatives.

The Division for Developmental Disabilities generally agreed that the residents should not move to nursing homes and began a process to identify other community settings for each resident based upon their needs and wishes. The Legal Center contacted the families and guardians of each resident and offered our help in this process. The families of 25 of the residents wanted our help and we attended each of their individual planning meetings throughout the fall and winter.

It soon became clear that the unit could not close as early as February 28 if it was to properly transition the residents. Committed to ensuring that individuals were placed appropriately and according to their wishes, the Division for Developmental Disabilities moved the closure date to the end of April. Throughout the planning meetings, the staff of the GJRC focused on identifying each resident's needs and offering choices for community placements.

Out of the 32 individuals only one was referred for a nursing home placement and that was to allow her to be closer to her family in a rural area of Colorado. Our staff visited the nursing home to assure that it could meet her needs. The other residents have generally been referred to group home placements. Mesa Developmental Services, the community centered board (CCB) in Grand Junction has shown leadership by building three group homes in Grand Junction to accommodate the significant needs of 23 of the skilled



# Sister Act Section

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nursing home residents. Three residents will remain at the GJRC, either in GJRC community group homes or other units on the campus. One person has moved to Montrose and will be served by Community Options, the local CCB. Another person will move to a community setting in Greeley. There are three people who are still awaiting an appropriate placement, but they will not be discharged from the GJRC until a placement can be found.

The Legal Center has committed to assisting with transition planning until all 25 individuals who requested our help have new homes in the community. We will continue to assist the residents who have not yet had placements identified and ensure that they receive appropriate services while they continue to live at the GJRC. We have also committed to follow-up visits to each placement to assure the residents are being appropriately served and are safe.

Finally, it should be noted that the Division for Developmental Disabilities and the staff of the GJRC have worked to ensure that the residents and their families are involved in the planning process and have choices regarding community placements. Likewise, Mesa Developmental Services has stepped up to develop community-based homes to meet the complex needs of these individuals. Family members, other members of the Grand Junction community, and The Legal Center have actively participated in an advisory committee to provide feedback regarding the transition process. The work is not done but we hope that this careful and inclusive planning process will result in people successfully and safely moving into the community.

*Randy Chapman, Esq., is the director of legal services at The Legal Center.*



Photo credit: Avinda Blarman

## Looking Ahead— Regional Forums

The Colorado Developmental Disabilities Council and The Legal Center for People with Disabilities and Older People are gathering information for the Council's next Five-Year Plan for 2012-2016 and for The Legal Center's setting of future priorities. We want to know what issues are important to people with disabilities and family members so that the Council's next Five-Year Plan and The Legal Center's priorities reflect those issues and concerns.

The Legal Center and the Council are gathering information in a variety of ways.

- We are very excited about the six regional forums that will be held around the state of Colorado between now and the end of September 2010. The forums will be held in Alamosa, Denver metro area, Fort Collins, Glenwood Springs, Greeley, and Lamar. The dates and locations for each forum will be posted on the Council's website as they are scheduled. The forums will offer participants an opportunity to hear about new ideas and promising practices in the nation as well as in Colorado.
- A survey asking for information on what are the most important issues and concerns for people with disabilities and family members will be posted on the Council's website.
- The Colorado Developmental Disabilities Council and The Legal Center will be conducting focus groups in each of the six regions as a part of the regional forums.



# I am autism, too. Thought on neurodiversity and the cure



I wrote this in response to a parent's note, but on second thought, I thought perhaps I should share it more widely . . .

For many of us on the spectrum, a parent's stated quest to "cure" autism feels sort of like a divorced parent constantly criticizing her ex in front of us kids. As that kid, I know I am half Dad, and half Mom. So when Mom tells me Dad is no good, what is she saying about me? For those of you who think this is metaphor, let me assure you it's not.

If much of my life is defined by autism, and autism is a terrible thing, how do you think I will feel about myself?

I ended up in special classes because I am autistic. I flunked out because I am autistic. I already know I am disadvantaged with respect to others who are not autistic. I don't need more stuff to feel bad about.

I want useful help. I want to learn how to hold a conversation, how to make a friend, how to get a job. Practical skills are what I need, not moral judgments.

That's why it is vital to embrace neurological difference. It is not going to go away, whatever a parent may wish. Demonizing the way we are only makes us feel bad.

And that's not all. I am a logical fellow. When I consider the situation, it's obvious that autism is not evil. It's not good or bad. It just is. There is no morality hidden inside neurological difference. It's not logical.

It's taken a lifetime to begin to understand the myriad ways that autism has shaped me. Indeed, as an adult, it's just one of the things that make me who or what I am. It's easy to dwell on what I can't do, and from there I can surely blame autism or anything else for my failure. But I know that's not a line of thinking that leads anywhere. So I try to focus on what I can do, and it makes me feel good to say, "See this great gift I have? It's because I'm autistic!"

Maybe you don't agree, and maybe it's not even a gift in your opinion, but why not let me have my joy over that bit of being?

Life goes better for all of us if we change what we can, and accept what we can't with some semblance of a smile.

There is nothing wrong with wanting to take away a disability. That's a great goal, and one I fully support. What's wrong is making something out to be "bad," and then failing to take it away; leaving us stuck with the "bad" irremovably bonded to us.

Moral judgment has no place in the world of remediating disability.

<http://jrobison.blogspot.com/2010/04/i-am-autism-too-thoughts-on.html>

*John Elder Robison  
Blog posted on April 12, 2010*

# New Disability Care Coordination Organization Now Enrolling Clients

By: Kelly Wilson Bossley



The Colorado Alliance for Health and Independence (CAHI), a nonprofit organization created by individuals with disabilities and their families, is proud to finally make the vision of improving the quality of lives through disability care coordination a reality.

For many individuals with disabilities, the current

healthcare system does not provide the necessary level of attention, often compromising both health and independence. CAHI seeks to provide an alternative in Colorado by coordinating health care services and integrating community services as needed.

After years of research and planning, CAHI began a pilot program in January to provide services to Medicaid clients in the Denver metro area. CAHI board and staff members are using their varied experience to bring the knowledge of disability to the coordination of care.

Mark Simon, a fierce advocate for the disability community for over 25 years, was one of the organization's founders and is currently serving as board president. He said he became involved in CAHI because he knew from firsthand experience how frustrating the healthcare system could be and thought a consumer-controlled organization could make a real difference. "This program is going to have a significant impact because individuals with disabilities are able to be in control of their healthcare," Simon said. "We want to get clients what they need, when they need it, without any denial by harassment "that often occurs in the Medicaid system."

Through Care Coordination, CAHI provides clients with more resources to better meet their health care needs and assists with any additional needs they may have related to community based services, such as transportation, home modifications or attendant care.

Adults on Medicaid, aged 21-64, who receive Social Security Insurance and are on the Home and Community Based Services (HCBS) waivers for brain injury (BI), Elderly, Blind and Disabled (EBD), or mental illness (MI) are eligible for the CAHI program. Enrollment in CAHI does not cost clients anything because the organization is paid on a per member, per month fee by Medicaid to provide care coordination services, and physician reimbursements are not affected.

## CAHI works with clients and the doctors of their choice to:

- Access all types of available care from acute to community-based services.
- Develop a self-directed care plan that addresses clinical, social, and personal needs.
- Assess individual risk factors related to disabilities and respond to urgent health needs.
- Maximize health, functioning and self-sufficiency to enhance their ability to live independently in the community.
- Better manage complex health care needs through education and support.

CAHI's program builds upon the success of other programs that have been implemented in other parts of the country while respecting the culture, geography and regulatory environment of Colorado to better serve people with disabilities.

While the pilot program is currently only serving the Denver metro area, the organization plans to expand to other parts of the state later this year. For more information, call a CAHI Care Coordinator directly at 303-694-7744 or visit [www.coahi.org](http://www.coahi.org).

## CAHI—"Bringing the Knowledge of Disability to the Coordination of Care"

*Kelly is CAHI Director of Policy & Communications*



# Lissie's Story

## Self-Employment Success Story

### Lissie's Luv Yums

(Gourmet Dog Treats)

When Lissie Clark graduated from high school, she knew three things:

- She did not want to work in the fast food industry;
- She liked animals; and
- She wanted to promote awareness and prevention of fetal alcohol syndrome.

She started a dog walking service and was doing pretty well, walking three dogs, but she knew she could do better. She wanted to give her charges treats, a good tasting dog biscuit that she made herself. She talked to her mother and a friend about it, and together they began to develop a recipe, testing it on a friend's dog. The biscuits were to be made from only the very best ingredients (flour and wheat berries from Wheat, Montana exclusively), and were to be decorated with beet juice hearts. They began manufacturing them in their kitchen using the family's mixing bowls, cookie sheets, and oven. Lissie was already thinking bigger. She was going to expand her business into "Lissie's Luv Yums," and promote awareness through presentations to groups who wanted to know about her business and her disability.

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**In the following three years, what had been a product which was sold only in Great Falls, Montana through the local flea market and friends, has expanded...**

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In order to expand the business, she needed funding for packaging materials, promotional materials, equipment, and a video public service announcement that would act as an advertisement for the products and to advocate for women to abstain from drinking when pregnant. She found the money through a Jobs Training Partnership Project and The University of Montana Rural Institute which granted money to people with disabilities who wanted to start their own businesses. **Lissie, her mom, and their friend started "Lissie's Luv Yums!"**

In the following three years, what had been a product which was sold only in Great Falls, Montana through the local flea market and friends, has expanded to a company which has customers in many locations in Montana and 15 other states, has a public service announcement (PSA) which is aired on the local Montana TV stations, and has a variety of products, including buttons exhorting "I Luv Lissies Luv Yums." Lissie and her mom make presentations to national conferences that highlight self-employment for people with disabilities in Montana, Nevada, and North Dakota. They also participate in fund raising events for Native Americans. They contract with employees to help them manufacture the products, have a mix so you can make your own biscuits, and have begun to contemplate other products related to people's beloved pets.

**Visit the website: <http://www.lissiesluvyums.com>**

This story is posted on the University of Montana Rural Institute's website at [http://ruralinstitute.umt.edu/lissies\\_story.asp](http://ruralinstitute.umt.edu/lissies_story.asp)

# SELF-EMPLOYMENT: ONE FAMILY'S JOURNEY TO MEANINGFUL EMPLOYMENT

By Sue Fager

There are many different employment strategies available for youth living with disabilities; self-employment increasingly is becoming a viable option and one worth exploring. The path to meaningful employment should begin with a discovery process that helps a young person and his or her family to determine potential career paths.

**Some basic questions to ask include: Who is this person? What motivates him or her? How does the person learn best? What are the individual's skills and interests? What support strategies work best? What works and doesn't work for the individual?**

Questions to help determine if self-employment may be an option to explore include: Does operating a business match the young person's skills and interests? Will operating the business teach him or her skills they need and want to know? Does the business enhance her or his standing in the community and present the respectable and valued image she or he desires? Can the business be adapted to provide the supports needed to be successful? Armed with the answers to these questions, possible career paths can be explored. The transition from high school to adult life provides a perfect opportunity to begin this exploration process.

## Poppin Joe's Kettle Korn Business

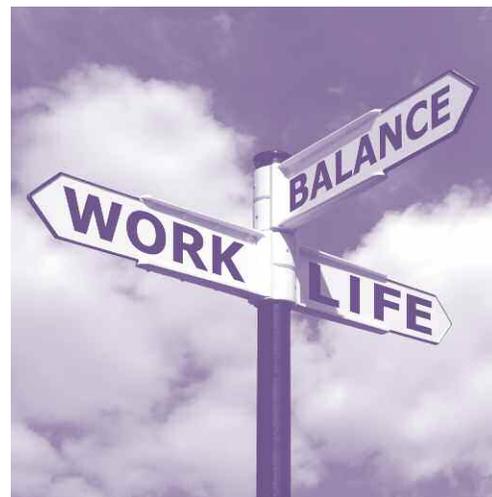
For the Steffy family from Kansas City, Kansas, the exploration process began when their son, Joe, was still in school. Before Joe graduated, his parents, Ray and Janet, began imagining a different future for him than what is traditionally offered to students living with significant disabilities. During

one of Joe's transition meetings they asked if the school could assist in designing a plan for Joe that included self-employment—the response they received was not a positive one. The team indicated that the only community employment opportunities they had to offer Joe included folding pizza boxes, restocking and bagging at grocery stores, and other similar experiences. His team had very low expectations for him and believed that he would probably never work or at best be employed in a minimum wage job. His parents had a very different view of their son's abilities:

“Basically, at Joe's birth, we made a promise to him that we would do all that we could to give him every opportunity to be what he could be. We wanted to give him a quality of life that was equal to that of his brothers and sisters. By the time he became a young adult, he would be part of the community around him and do and have friends like everybody else.”

His parents wanted Joe to have choices and opportunities rather than being “fit” into a system of existing services.

Joe, with the support of his father, tried two different community-based work experiences while he was in high school. One was feeding and watering horses at a local stable and the other was at the local pool. Joe's



parents felt that these experiences were helpful in determining the kinds of support for employment Joe would need after graduation.

Joe's parents also wanted to provide an opportunity for him to work in a small business venue.

An opportunity to purchase Kettle Korn equipment arose in 2000 and Ray and Joe began popping corn at Wal-Mart and at grocery stores throughout their city. This experience proved that Joe could work. Within a year's time, he had mastered all of the different parts of the process of making Kettle Korn.

Joe has limited speech, but his mother reports that while he was popping corn at a festival, she heard him call himself “Poppin Joe”. The name of the business was created and has been “Poppin Joe's Kettle Korn” ever since! Joe's business officially became a sole proprietorship in April of 2005.

While his parents are instrumental in supporting Joe in his small business, they are adamant that the business belongs to Joe and not to them. Joe produces his product and sells it at local events and at various business locations. Like any other business owner, Joe receives supports in completing various tasks that he cannot complete himself, including being driven into town so that he can independently go into the bank to deposit the proceeds from his sales as well as restocking his products at local stores.





# Book Review

By Mackenzie Helton

## The Journey Home from Autism,

by Rhonda Spellman, documents one mother's experiences with her son's autism. This is the story of Tanner, a child who changed a great deal after the vaccinations included in his well child medical appointments. His reactions included high fevers and rashes and, after the MMR (Measles, Mumps and Rubella) shot, a withdrawal from things that had stimulated and amused him in his first months. Rhonda didn't feel quite right about her son's behaviors and development but was constantly reassured by her husband, friends and the staff at her pediatrician's office that Tanner was 'fine'. After the arrival of a second son Rhonda had two boys, and their differences became more and more noticeable.

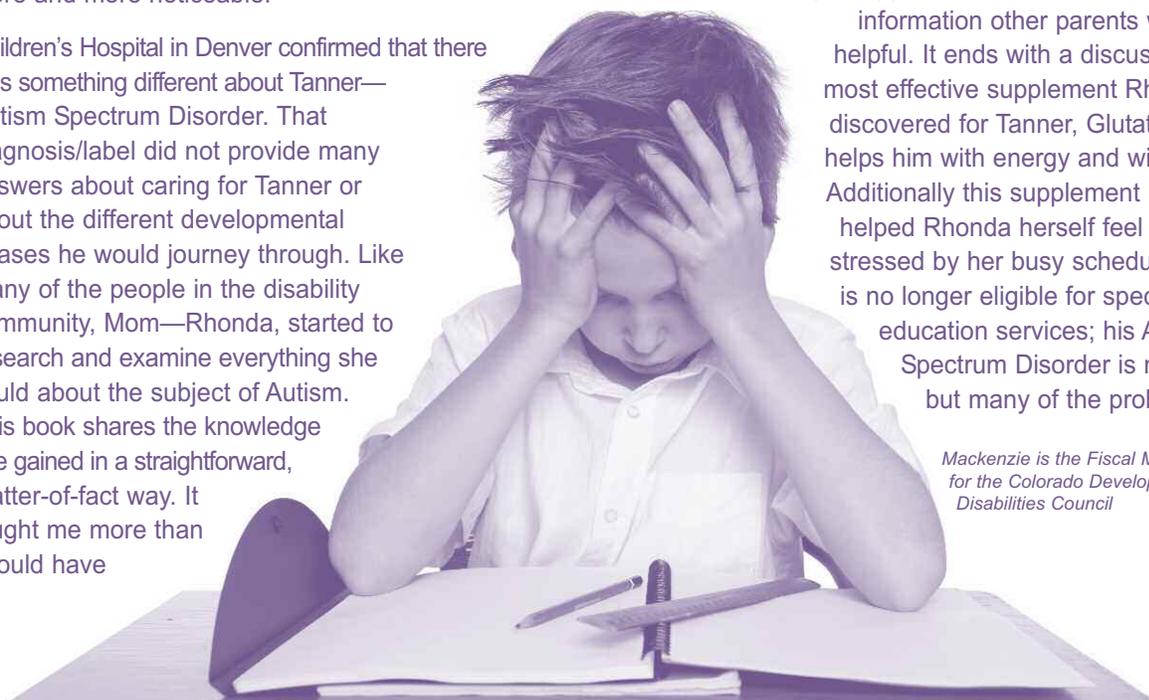
Children's Hospital in Denver confirmed that there was something different about Tanner—Autism Spectrum Disorder. That diagnosis/label did not provide many answers about caring for Tanner or about the different developmental phases he would journey through. Like many of the people in the disability community, Mom—Rhonda, started to research and examine everything she could about the subject of Autism. This book shares the knowledge she gained in a straightforward, matter-of-fact way. It taught me more than I could have

imagined about autism spectrum disorder. More than that, it reminded me how much parents do for their children.

Like so many others mother and son began the arduous task of learning about autism and what others had done. Included are things that worked and those that didn't work for this family. Rhonda tried the things she saw as working for other people, different therapies to help Tanner comprehend and learn, different teaching methods that followed his point of view. Then on to food and vitamin therapies related to real and suspected allergies. At this time she discovered many foods that cause problems and many more chemicals that hide in everyday products. Rhonda researched all of these extensively but usually trusted her instincts regarding which ones to try and which ones to avoid. Tanner currently enjoys a diet free from gluten (wheat products) and casein (dairy foods). Additionally, she discovered that mercury in vaccinations that were supposed to help Tanner avoid childhood diseases might have been instrumental in the changes he went through in his first years of life.

Rhonda spends a great deal of time with Tanner, who had written, illustrated and published his first book by the time he was five years old. Rhonda's book contains a section with recipes for gluten/casein free foods and a number of helpful Appendices with resources and information other parents would find helpful. It ends with a discussion of the most effective supplement Rhonda discovered for Tanner, Glutathione. It helps him with energy and with clarity. Additionally this supplement has helped Rhonda herself feel less stressed by her busy schedule. Tanner is no longer eligible for special education services; his Autism Spectrum Disorder is not gone, but many of the problems are.

*Mackenzie is the Fiscal Manager for the Colorado Developmental Disabilities Council*



## The Dan B. Davidson Award for Excellence in Inclusion honors Dan Davidson, whose very life defined inclusion.

Dan defied the odds, set aside the advice of others, and followed his dream to live independently in the community. In honor and recognition of Dan's spirit, the Colorado Developmental Disabilities Council recognizes exemplary practices of inclusion that support persons with disabilities to become fully participating members of their community.

Awards will be given to individuals, agencies or organizations that have demonstrated visionary practices—providing exemplary service and supports—for persons with disabilities that lead to inclusion as active and valued members of their communities.

The Council will recognize outstanding examples of inclusion in the following categories:

- Education
- Employment
- Community Life

Winners will be recognized at the Council's annual celebration on July 28th. Winners in each category will receive an award honoring their efforts, along with a \$500 honorarium.

Nominations must be submitted by June 17. You may submit your nomination online at <http://www.coddc.org> or call the Council to have a form mailed to you (720-941-0176).



## The Council's newsletter may be headed to your e-mail in-box

The Council is beginning the process of changing the distribution method for our free quarterly newsletter, *Between the Lines*—we are moving toward electronic distribution.

Beginning with the Winter 2011 issue, if we have your email address, you will no longer receive a printed copy in the mail. However, if you want us to continue sending you the newsletter by postal mail, please let us know and we will be glad to send it that way.

Please contact us to let us know your preferences regarding delivery of your subscription to *Between the Lines*. You may call us at 720-941-0176, fax us at 720-941-8490, or email us at [cddpc.email@state.co.us](mailto:cddpc.email@state.co.us). Alternatively, you can send us a note at: CDDC, 3401 Quebec St., Ste. 6009, Denver, CO 80207.



# Search Selections

The year the National Association for the Self-Employed (NASE), (<http://www.nase.org/Home.aspx>) was established: **1981**

Number of businesses and employers, respectively, represented by the U.S. Business Leadership Network (<http://www.usbln.org/>): **60; 5,000**

Number of years Kettle Korn has been a food delicacy in the United States: **234**

Number of musical groups named "Safety in Numbers": **1**

Number of entries in a search engine search for the phrase "Better Safe than Sorry:": **4,680,000**

Number of entries in a search engine search for the phrase "Pet Safety": **65,900,000**

Name for person behind home plate who declares a runner 'safe': **umpire in chief**

The year the Fair Housing Act was amended to add protections for people with disabilities: **1988**

Year the National Dropout Prevention Center/Network was established: **1986**

Year the National Dropout Prevention Center for Students with Disabilities was established: **2004**



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