

# BETWEEN..... .....THE LINES

Spring 2006

COLORADO DEVELOPMENTAL DISABILITIES COUNCIL

## TWO GLANCES

*The second glance will make all the difference in the world to the individual in receipt, as will the first.*

She was loading the potatoes and the fish and the half and half from the cart to the counter in an attempt to speed the check out for the weekly drudgery of grocery shopping. Once all the items were unloaded from the cart, she turned her attention

to the bagger who provided her no surprises in her choice of plastic or paper. The bagger continued his job of filling the bags with one unexpected exception—he stopped and flapped his hand between bagging the half and half and the potatoes. The cashier then rolled her eyes in annoyance at this difference that she passed down the row of cashiers, each making note of the annoyance, of the difference, of the embarrassment. The glance indicated that a line had been drawn in the sphere of acceptance by other co-workers. It was unlikely that the bagger was going to be let in on the message to gather at the bar for drinks after work. Given the glance, it was unlikely that someone who had intended to extend an invitation to the bar would feel comfortable doing so now. At that instant, the die had been cast with the glance and the bagger became relegated to strictly physical presence for his eight-hour shift each day. The shopper took note of the event with wonder that things stay the same, that prejudice against difference perpetuates again and again.

The Saturday could have been an otherwise dull day had the evening not included dinner out with a friend. The outing would hopefully break the routine of errands, cleaning the house, and doing laundry. The shopper joined a friend for dinner, taking a window seat to watch Colfax go by. Just as they were picking up the menus,

her dinner partner noticed someone she knew passing on the street and knocked on the window to wave. The person on the street was also someone who was different—who may do something like flap his hands, or talk loudly, or wear unkempt clothing—someone who may just get a glance and cause some discomfort in others. The discomfort was already rising in the couple, as it became clear that the person was going to enter the restaurant and have a conversation with them. This would no doubt draw undue attention, cause the otherwise distracted crowd to stare at the three of them, and some judgments would then be cast on all of them. This was not the intention of the wave.



At that point, the server passed by to take orders and glanced at the new addition to the table with acknowledgement and a welcome. The glance made an immediate difference in putting the seated couple at ease as well as setting a welcoming tone. The third guest was clearly an old customer whose first name and favorite item on the menu were known by the restaurant staff. The server's glance was very different from the cashier's earlier glance at the grocery store. The second glance will make all the difference in the world to the individual in receipt, as will the first. The first glance will relegate the bagger to either days of isolation in his work place, or, worse yet, cause the job to fail and send the bagger back to riding the van on field trips and to fast food restaurants. The bagger may have very little to do or say about his success or failure in such a work environment, but the glances will.



# Newsletter



# Colorado's Autism Waiver

Colorado Medicaid is in the process of developing a waiver for young children with autism. Parents, advocates, providers and state staff have worked diligently to create early intervention for young children, birth to 6, who have a medical diagnosis of autism and who have or qualify for long-term care under Medicaid. A team approach, including parents, will design plans to provide such services as occupational therapy, speech therapy, psychological and psychiatric services, physical therapy, and/or behavioral therapy. The Home and Community Based services provided would include only those services itemized in the child's care plan and will be limited to no more than \$25,000 annually. Approximately 70 children per year will be served. The intent of this waiver is for families to be able to choose supports and services that best meet their needs and values. Given the limits on funding amounts and the number of children to be served, families will need to continue seeking additional resources, including private insurance, schools, Child Find, Early Childhood Connections, Family Support Services Program, and other supports and services, generic or otherwise, that might be helpful.

Families interested in this waiver should apply for Medicaid if their child has or qualifies for SSI or the family income would qualify the family for Medicaid. Other steps include contacting the Autism Society of Colorado at 701 South Logan Street, Suite 103, Denver, Colorado 80209 or your local Arc or ACL. Those organizations are committed to informing families about next steps and when applications for the waiver will actually be available. The Autism Society is informally collecting names so they can let families know when the waiver is up and running.

Additional information is being posted to [http://www.autismcolorado.org/autism\\_waiver.htm](http://www.autismcolorado.org/autism_waiver.htm) and <http://arcrapahodouglas.org/news/pdf/AutismWaiver.pdf> as it becomes known. With the knowledge that many young children benefit significantly from early services, and may need less support during their lifetime because of them, this is an exciting opportunity for Colorado.



## Advocacy

Is to speak to a matter or issue on behalf on an individual, or group

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in a manner which is vigorous and vehement (and with wisdom)

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which involves an element of distinct cost to the advocate

Potential costs:

- ❖ Time
- ❖ Wear and tear on emotions
- ❖ Investment of materials
- ❖ Risk of incurring disdain and resentment, rejection,

+

And is free from conflict of interests

(definition provided by Susie Walton, former Council member and resident of Evergreen, Colorado)

# "A CASE FOR INCLUSION"

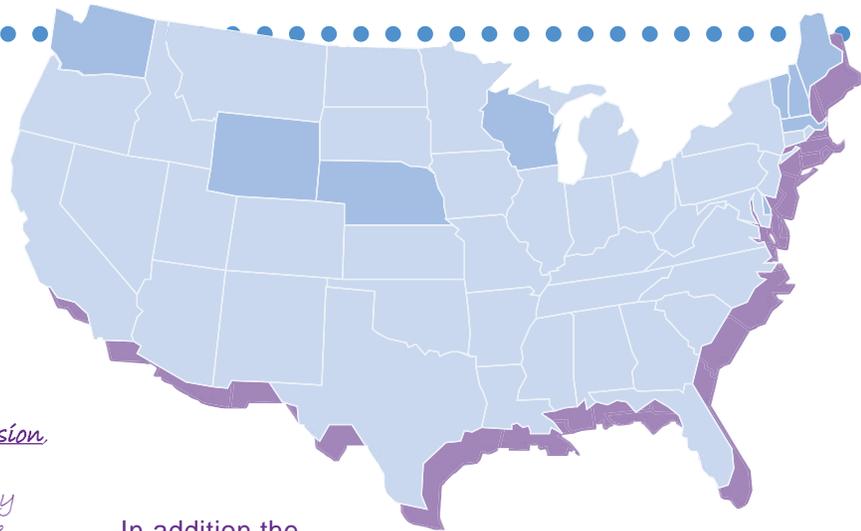
WASHINGTON, March 1 /U.S. NewsWire/— United Cerebral Palsy, one of the nation's largest health charities, released a new national analysis of state Medicaid services for people with developmental disabilities and mental retardation on February 28. The report, titled A Case for Inclusion, includes state rankings for all 50 states and the District of Columbia, as well as letter grades in key areas of Medicaid service delivery including Home- and Community-based Services, Small Residential Settings, Reaching Those in Need, Services Self-Directed, and Cost Efficiency.

(Full state rankings are available at <http://www.ucp.org/medicaid>)

While indicating states have varied approaches to Medicaid service delivery, the report clearly reveals that top-performing states emphasize community inclusion for people with developmental disabilities and mental retardation. New Hampshire, the top state in the United Cerebral Palsy report, spends over 98 percent of Medicaid dollars to support people living in their communities through home- and community-based services. On the other hand, Texas, which ranked last, only spends about 31 percent.

"States that make community inclusion a priority perform significantly better in our analysis," said Stephen Bennett, President and CEO of United Cerebral Palsy. "The best Medicaid programs produce outcomes that enrich the lives of people with disabilities, while promoting self-sufficiency. And states that focus on individuals and families are often more cost effective than others that promote institutionalized care."

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In addition, the report shows that successful states support the smallest possible and most home-like residential settings in communities, assist individuals transition from Medicaid to work, give people the ability to direct their own services, and utilize nationally-recognized quality assurance programs. Nevertheless, A Case for Inclusion concludes that all states have room for improvement. No state received a top grade in all service categories. "Many states still direct a major portion of limited Medicaid resources to supporting individuals with disabilities in large, often costly state-run institutions," said Tarren

Bragdon, an expert in healthcare policy and author of A Case for Inclusion. "The data is clear.

Too many Americans with disabilities are still denied the opportunity to fully participate in and be a part of their communities." Another key finding was that top- and low-performing states were politically and economically diverse. The political make-up of state government, the state's tax burden and even state Medicaid spending per capita did not dictate performance in the United Cerebral Palsy analysis. New York, for example, had a high overall tax burden of 12 percent, second only to the District of Columbia, yet ranked 36th in the Medicaid analysis.

United Cerebral Palsy will use the report to encourage people with disabilities, advocates and officials at all levels to focus Medicaid debates on the effectiveness of services, rather than just budget

.... people with developmental disabilities and mental retardation are among Medicaid's most vulnerable beneficiaries.

numbers. The organization will use the data collected to create state-level action plans for its nationwide network of affiliates to work with state governments to improve Medicaid programs in their regions.

Nationwide, Medicaid serves almost 530,000 individuals with developmental disabilities and mental retardation, spending \$27.4 billion in fiscal year 2004 or almost \$52,000 per person per year. While individuals with developmental disabilities and mental retardation make up just over 1 percent of all Medicaid recipients, services to the population account for nearly 10 percent of all Medicaid expenditures. In addition, people with developmental disabilities and mental retardation are among Medicaid's most vulnerable beneficiaries.

*The top ten states include:*

1. New Hampshire
2. Maine
3. Massachusetts
4. Vermont
5. Alaska
6. Nebraska
7. Washington
8. Delaware
9. Wisconsin
10. Wyoming

More than 230 unique data sources and guidance from national disability experts were considered to create comprehensive state snapshots. The full United Cerebral Palsy report, *A Case for Inclusion*, and in-depth state-by-state analysis are available online at <http://www.ucp.org/medicaid>

# Utilizing the Strengths of Families of Color



In my work with families and communities over the past 20 years on issues related to disability, special education, educational advocacy, capacity building and access, familiar barriers for families of color emerge with great consistency. It was this work with underserved families in Boston and around the United States that prompted me to found Urban PRIDE.

Urban PRIDE is a community resource center established to improve the availability of, and access to culturally responsive disability related support, information, and training for young adults with disabilities and diverse families who have children with disabilities in urban Boston. We work with families in ways that build on their strengths and the existing resources in the community.

Our goal is to support traditionally underserved, multicultural families and young adults impacted by disability to better access and derive greater benefit from typical community resources and disability-related services and supports. These include early intervention and early childhood education programs, regular and special education programs, transition/ post-school planning, after-school and summer programs, health care, social/recreational, and independent living resources.

While it is true that all families of children with disabilities are underserved in some respect, there is no denying the unique barriers to access for culturally and linguistically diverse families, especially those defined as low income. "Due to a disturbing lack of hard data on minority populations with disabilities, it is not certain precisely how many members of minority groups have disabilities or how fast this population is growing," (National Council on Disability, 1993, page 3).

The National Council on Disability (1999) indicates that virtually every federal estimate of the incidence of disability among people from diverse cultures in the United States is

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likely to be low. This report further indicates that these low estimates appear to substantially impact the effectiveness of service delivery.

We can and must develop and initiate parent support and engagement practices that reflect the values and social practices of the people and communities we work with. We can both demystify the service maze for families, and support them to advocate successfully within those systems by outlining the assumptions and culture-bound constructs that determine services. We can help them to understand and voice the dissonance they experience in their interactions with systems.

We make our own assumptions to explain why parents won't do what we want, why they don't participate at the level and in the ways that we want them to participate, or don't value and take advantage of the opportunities for participation extended to them. But we frequently are blind to the cultural values that are embedded in our interpretation of families' actions.

## Non-participation as protest

In the first three years after I founded Urban PRIDE, I was startled at the number of families that came to our attention that had not participated in an IEP meeting at their child's school for one or more years (almost one out of every three families). Once I began to work with these families, supporting them to secure and, in some instances, untangle, the web of evaluations, IEP's, progress reports, written communication, and other documents that are part and parcel of the reality of having a child with a disability receiving special education services, I began to see a pattern. What was surprising was the numbers of rejected IEP's in years prior to even this period of non-participation.

*.... "I began to feel that to continue to participate was to sanction what I felt was not in the best interests of my child."*



When I asked, "why have you not attended meetings, why did you reject so many IEP's?" responses were surprisingly consistent. In one way or another most felt that rejecting their child's IEP and/or not participating in IEP meetings were their only means of protest. I was told, "I went to meetings, but my questions would not

be answered," or, "they simply offered the same services no matter what I said," and "I began to feel that to continue to participate was to sanction what I felt was not in the best interests of my child." When there same families were provided with the information and, more importantly, the support they requested, they participated not only in annual IEP meetings but multiple meetings, in and out of school.

## Presence does not equal access

With traditionally underserved families of color, parent training is often the primary strategy to facilitate parent participation.

Yet, it is often done in isolation to or out of context with the community, culture, and lives of underserved families. This observation became my guide to revising our strategy for information dissemination activities with families. Over time, it has become apparent that families' personal interaction with staff was the primary means of applying and acting upon their developing knowledge and skills.

In these interactions, e.g. face-to-face meetings, small group trainings, roundtables, or even by phone, staff serve as coach and advocate for families. In subsequent meetings with parents, we were frequently told "I learn more talking with you and going to meetings with you than all that paper you gave me."

At Urban PRIDE, we have revised our training formats to emphasize facilitated roundtable discussions. During each roundtable discussion, we explore a single topic in greater depth than is otherwise possible in a two-hour setting. In this way, the natural relationship between the specific topic and the inter-relationship to the overall process reduces the complexity of the special education process for families.

Families select the topics that will be explored at each roundtable. The number and nature of handouts have been reduced and revised, and discussion templates are utilized which participants use to articulate specific questions and concerns relative to the topic. Families share their specific concerns and questions with the group, and receive answers and strategies not only from the facilitator, but also from each other.

## From “Me and Mine” to “We and Ours”

This two-way approach of sharing information and training through individual/group coaching and mentoring strategies, rather than the one-way approaches such as traditional training and advocacy, have proven to be an effective strategy for supporting families to put into practice their newly acquired skills on behalf of their children.

Another outcome of the process is that families naturally move from seeking answers relative to their individual

child and move to questioning why things are the way they are in the larger sense. They shift from seeking an advocate to work with them on behalf of their own child/ren, to moving towards collective action to address the challenges in a more systemic fashion.

Working with families of color requires an understanding and valuing of cultural dynamics. Low economic status exacerbates the challenges to engage and develop advocacy skills of the family. We can utilize the tool kits of citizen participation and adult learning to build our capacity as professional in working with families of color.

—Charlotte “Dee” Spinkston is the founder and director of Urban PRIDE.

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## The Multicultural Committee is Pleased to Announce Two Leadership Training Projects

The Colorado Developmental Disabilities Council has granted funding to two programs that will be focusing their efforts on leadership development in the Latino and Black communities over the next year.

Parent-to-Parent of Colorado will be working in the Park Hill, Green Valley Ranch and Montebello neighborhoods in Northeast Denver. **The project aims to create a twelve-member leadership network of Black parents of children with disabilities and/or special healthcare needs.** Eight to ten information and training sessions will be provided for the community at large. Trainers from the Black community who will serve as presenters and mentors will conduct these sessions. The twelve members of the leadership network will develop individual leadership plans with support and mentoring from Project Coordinator Bridgette Larkin. One component of the leadership plans will be the mentoring of other Black family members in the community.

**The second project is a collaborative effort between Families and Allies Working Together and El Grupo Vida, with a dual focus on leadership development in the Latino community and board development for people with disabilities, family members and community members of each board of directors.** The project will conduct two training sessions in Spanish that will give an overview of the service system, with written materials provided in Spanish, so that families can make wise choices. Additionally, there will be two one-day workshops that will assist Spanish-speaking individuals in becoming proficient at facilitating Future Plans and activating Personal Networks, and classes in computer literacy. The project will also include three leadership-training sessions with the board members of El Grupo VIDA and Families & Allies that will assist them in their roles as leaders of these two grassroots, nonprofit organizations and as future leaders of other community organizations.

The Council’s Multicultural Committee issued the requests for proposals that resulted in the funding of the two projects, and will provide technical assistance to the projects. The committee welcomes new members and visitors to the monthly committee meetings. The Multicultural Committee meets every fourth Tuesday of the month from 10 AM to Noon. Please call the Council (720.941.0176) for more information on attending the committee meetings.

# Mentionable Markings

**Year in which the Medicare hospital trust fund will be "completely exhausted," according to the trustees: 2019**

**Year in which trustees predicted in 1991 that the fund would be exhausted: 2005**

(Centers for Medicare & Medicaid Services, Baltimore, August 2004)

**Minimum number of prescription drugs currently under investigation for Medicaid price-gouging or marketing fraud: 500**

(U.S. Department of Justice, September 2005)

**Percentage markup that Abbott Laboratories charged in 2001 on solutions of sodium chloride, i.e., salt water: 20,735**

(Harper's Index, September 2005)

**Rank of the U.S. health-care system among the most efficient in the world, according to the World Health Organization: 37**

(World Health Organization, Geneva, February 2004)

**Percentage of lawsuits decided last year under the Americans with Disabilities Act that were won by employers: 94.5**

(American Bar Association, Washington DC, March 2004)

**Number of Californians with disabilities whose home aid the Governor plans to eliminate: 65,000**

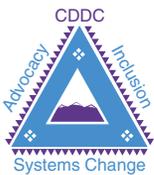
(California State Department of Social Services, March 2004)

**Rank of Texas among states in which the largest percentage of citizens lack health insurance: 1**

**Rank of Colorado: 14**

**Rank of Minnesota: 50**

(U.S. Census Bureau, Washington DC, April 2004)



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