

BETWEEN.....THE LINES

WINTER 2001

COLORADO DEVELOPMENTAL DISABILITIES PLANNING COUNCIL

COLORADO DEVELOPMENTAL DISABILITIES PLANNING COUNCIL MEMBERS

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elcome to the renewed Council newsletter! The Council is fully staffed, our requests for proposals have been filled with contracts in place, our committee structure is again active and we are ready to deal with systems change issues and the legislature. Please see the attached column with the listing of our Council members. We are thrilled with the Governor's appointments to the Council and have managed to acquire an incredible staff.

For those of you who may be unfamiliar with the Council, we will review our essential charges. The Developmental Disabilities Planning Council is federally funded through the Administration on Developmental Disabilities in D.C. We are funded through the Developmental Disabilities Act, as is JFK, the Colorado Center on Excellence, which is responsible for research related to disability, and the Legal Center, Colorado's Protection and Advocacy program. The charge of the Council is to work with our community in systems change relative to policy, the legislature, and Congress. A second charge is to fund various grants that will assist in creating system change and have the capacity for implementation statewide. We also co-sponsor various conferences, give start-up funds to grassroots organizations, and sponsor training events through the Consumer Involvement Fund. Thus we are sometimes seen as the bank and, secondly, as a systems change agent. We hope to reverse that perception over time.

The Council has tried to streamline a few of our procedures that will require some changes in response by groups requesting funding from the Council. Our Five Year Plan priority areas are transition from school to work (thus including both education and employment), and community inclusion, which is addressed by various projects. At this time, all of our requests, except self-advocacy, are filled and we do not anticipate others going out in the near future. A chart of our expenditures is included at the end of the article. We also have \$20,000 in executive committee funds to use to support grassroots efforts. These requests are granted quarterly and are due the first of the months of January, April, July, and November. We are unable to retroactively fund events. Thus, if you are holding an event in June, you need to submit the proposal by the first of April. Our Consumer Involvement Fund is available to families and individuals with disabilities for training events. In addition, we directly fund eight conferences to ease the billing process. They are: Association for Persons in Supported Employment, Brain Injury Foundation, Colorado Cross Disability Coalition, Colorado Department of Education Part C, Developmental Disability Community Conference, Assistive Technology Conference, Deaf Symposium and PEAK Inclusion Conference. If you want scholarship monies for these events, please make arrangements directly with the conference organizers.

Lastly, we hope you will join us in our efforts and critical activities around health care reform, education, the justice system, employment, community inclusion and the implementation of the Lois and Elaine (Olmstead) decision. The Council's small staff and even smaller grant budget can only be enhanced by your cooperative efforts and outreach to become involved in system change.

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..... Newsletter

LIFE STORY

Since I began to communicate via typing in October of 1991, shortly after my 13th birthday, I have shattered many walls, both inside myself and in the world around me. I've had to overcome many prejudices, both from others towards people with disabilities as well as my own towards those who don't have any labeled disabilities. I've had to fight for the right to the education I'm supposedly guaranteed by law... and for the chance to overcome the beliefs of many skeptical and cynical individuals within the media and the medical and educational communities.

When I first started typing in October 1991, I had spent in excess of 11 years with no way to communicate. I couldn't nod, speak, or use sign language effectively because of my "dyspraxic inertia." I had also learned how to live DOWN to expectations of others, including teachers, medical and therapy professionals, so-called friends, and family. People fully believed I was "hopelessly retarded" since I couldn't express myself or respond in any acceptable way; and to all outward appearances, that's exactly what I was. When I first started to type, I needed my hand held and index finger supported. Over time, I moved to wrist support, elbow support, a hand on my shoulder, and just having someone's hand "shadowing" mine.

All these kinds of "facilitation" made it easier to overcome my inertia; but they also caused people to question whether it was my hand or that of my "facilitator" actually typing. I finally became an independent typist because of those doubts and the powerful inner drive to live UP to my OWN expectations! Since I began communicating in the fall of 1991, I've taken many difficult leaps in order to conquer walls in areas such as independence, emotional maturity, socialization skills, and trust. What was probably my most difficult leap was from "retarded" school to accelerated seventh grade classes in a regular junior high school. And one short year later - high school, which I finished in a mere three years! High school was, indeed, a learning experience on every level and for everyone involved. I had to modify what others regarded as bizarre behavior in order to fit in with my peers, be accepted by my teachers and administrators, and not get kicked out of classrooms (which happened more than once), or suspended from school, which actually happened once. I also had to manage to stay true to myself while doing this, a daunting task for anyone, to be sure.

After graduation, I passed the English Entrance Exam for college with high honors. In the fall of 1997, I leapt into college at SUNY Rockland and have been an A student

thus far for three plus years at both Rockland and Denver University, despite initial obstacles such as the need for extended time and a quiet setting for testing. I have been both the victim of 12 years of total exclusion and four years of so-so inclusion in education and am now the extremely happy and fortunate beneficiary of in excess of three years of superior inclusion in college. I publicly praise my colleges, the State University of New York at Rockland and Denver University, for having treated me with respect and dignity and making me feel welcome, successful and fully included as a member of the academic and social community.

I've neither asked for nor received preferential treatment and I enjoy being viewed as and treated almost exactly like every other student in both regular and honors program classes, with few brief exceptions to this rule. I have gained greater self-esteem, self-confidence and pride, enabling me to achieve even beyond my own original high expectations and internal standards. My professors and classmates befriend and accept me as the person I am, eccentricities and all. They no more expect me to conform to their behavior than I expect them to conform to mine. We are learning from each other, and that's the way it should be!

In my freshman year, in March of 1998, I was chosen to represent SUNY Rockland at a prestigious conference for the Center for the Study of the Presidency in Washington, D.C. My attendance at this conference as the only student there with a noticeable disability was a surprise to me, just as I'm sure that I was a surprise to those who met and spoke with me. After all, most of the "verbalizers" of this world never even come into contact with a person who needs to use a keyboard device to communicate. In this impatient society of ours, few people ever seem to have the time to wait for me to finish expressing myself through my slow, one-fingered typing before leaving my presence.

I may or may not fulfill my new goal of being a neuropsychological researcher, I may or may not change my mind about my career, I may or may not get married and have kids, but ultimately I will do anything my heart desires and to which I aspire; ultimately, that's all up to me, just as it should be to everyone! I'm lucky I can hear and extremely fortunate to have a communication device of my own that enables me to "speak." I believe these should be made available to all people with communication and/or hearing impairments. They should be equipped with voice output in a variety of voices as well as visual and/or printed output in case the person to whom you are communicating also has a hearing impairment. Children should be given them and trained in how to use them at the earliest age possible, and

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BOOK REVIEWS



A Review of *Bowling Alone*

by Robert Putnam

Reviewed by: Stephen R. Hall, Executive Director,
The Resource Exchange

Somehow, in the last two decades community groups, associations, and the contacts and connections they provided began to fade. De Toqueville in 1803, called America "a nation of associations." Instead, just over the last two dozen years, we have become a nation that spends a lot of its time sitting alone in our homes watching the television.

I believe the successful inclusion of people with disabilities in the everyday life of our communities is directly wedded to what Robert Putnam has called our current revival of the "American Community." In *Bowling Alone*, he helps us remember a time when we did things together; in leagues, in clubs, and associations with others. Relationships, friendships, contacts, and connections are developed when we join golf leagues, bowling leagues, play cards regularly and talk with each other. Those environments are rich in what Putnam has called "social capital." Social capital is our lifeblood for successfully connecting people with disabilities to their community.

Through decades of research, Putnam has found the culprit, the single reason for our declining social capital - again, it's watching television. Unlike our parents who chose what they wanted to watch, then watched it, we turn it on "just to see what's on" and let the television tell us what we should watch. Like previous failing societies throughout all time, we have become a nation addicted to a powerful self-satiating "drug" that isolates us in our homes away from the friendships, relationships, contacts and connections of other community members. We have become a nation tuned in and tuned out.

For people with disabilities, already isolated by government sponsored transportation systems that direct billions of dollars only for those who drive automobiles and a pittance for everyone else who needs to get somewhere, Putnam's *Bowling Alone* is a national wake up call. Lest we suffer the same fate as other failed cultures, we must now turn off our televisions and help people with disabilities become members of clubs, associations, and other community groups as if their life - and our own - depended on it.

The Lost Children of Wilder: The Epic Struggle to Change Foster Care

By Nina Bernstein, reviewed by Marcia Tewell

The novel reports on the many arduous attempts to change the lives of children entrusted to the welfare/foster care systems, as well as the similarly futile attempts on the part of attorney Marcia Robinson Lowrey to use the legal system as a tool of reform. Wilder is the surname of a young woman (Shirley Wilder) who was placed into foster care at the age of 13 during a time when the practice was to send almost all child care money to private, mostly church-affiliated agencies. Catholic foster-care agencies gave preference to Catholic children, as Jewish foster-care agencies gave preference to Jewish children. Protestant children, especially African-American Protestant children in need, had to fend for themselves. Historically in the 1930's babies born out of wedlock between midnight and noon were Catholic and those born between noon and midnight were Protestant. It wasn't until the 1960's that Jewish voices were heard so that they then got a third of the foundlings. The lawsuit, filed in 1973, was based on placing children based on religion and convenience rather than need. The book also follows the path of Shirley's son, Lamont, through his journey in the foster care system and back to meeting his mother in later years.

The Lost Children of Wilder cites many journalistic, advocacy, and political efforts to reform the system as they impacted (or not) the lives of Shirley and Lamont. One such article, "Big Money, Little Victims," charged that agencies pleaded poverty in order to reap private donations while hoarding blue-chip stock portfolios, diverted money meant for care and denied children the chance to escape foster homes where rampant abuse occurred. Other findings supported by the Children's Defense Fund included a profitable interstate commerce with all but five of the fifty states involved in the trade. Only one third of the states ever sent case workers to check on the children and the children were seen as pawns in private attempts to gain wealth or governmental attempts to save money.

Lamont spent time in the Golden Valley Home in Minnesota, where restraints and aversives were used to control the behavior of the children in the care of the home. Like nearly every other complaint filed against Golden Valley during this time period, it was closed as "unsubstantiated - insufficient evidence." Golden Valley was not subject to any regular inspection or certification by any other state agency. Under Minnesota law, as long as the Joint Commission on Hospital Accreditation (JCHA) accredited it, it was deemed to be in compliance with all licensing requirements.

The book has many lessons in system change as the focus of the group being "served" is interchangeable with the elderly, disabled, juveniles in the correction system, or almost any other devalued group. Despite our current ever-stronger emphasis on the "cost" of people, there also has consistently existed a priority of money over people. The book is a great historical saga that applies to 2001 as well as to 1973.

The book is the newest addition to the library at the Developmental Disabilities Planning Council. Please feel free to call us at 720-941-0176 if you are interested in accessing our library resources.

Accommodation Puzzlers

- A fast food restaurant warns individuals with visual differences about the danger of hot coffee with a Braille message on the plastic lid: "hot coffee-decaf" or "hot coffee-regular."
- A restaurant owner asked, "Why would we need a ramp here? People in wheelchairs don't frequent our business."
- The educator of a student with the label of learning disability tells the student, "Just raise your hand when you don't understand, and I will explain it again."
- The New York State MR/DD Department has a policy that requires people who are non-verbal to prove literacy before they can explore the possibility of using facilitated communication (FC) as a means of communication.
- "Specially commissioned Braille posters with the theme of equal treatment for the blind were on display this winter at the Truro Leisure Center (Truro, England) and the University of Alberta (Edmonton, Alberta) human resources department. However, sighted people cannot read the posters because the words are only in Braille, and the blind cannot read the posters because in both locations the limited-edition posters were hung on the wall behind glass covers, to 'protect' them."
-Boulder Daily Camera, Sunday, April 19, 2001

Good Intentions Are No Excuse!

poster from Mouth Magazine

Why I believe in Inclusion

As one of the first children with significant labels to be mainstreamed in Denver Public Schools in 1976, I began my third grade academic year at my neighborhood school, Philips Elementary. Previously I had been "educated," I use the term loosely, at Boettcher School for Handicapped Children located across the street from The Children's Hospital. As I remember, not much teaching or learning took place although there was quite a bit of "curriculum" developed around behavior modification. I was under the false impression that I was extremely intelligent as I was in the fifth grade for academics at the age of 7, I also learned that I was terribly misbehaved and had better "shape up or else..."

My parents stopped just short of threatening a lawsuit against Denver Public Schools, in order to let me be "mainstreamed" and attend a regular school. Mainstreaming was an appropriate term for my transition to a non-segregated classroom setting. Looking back I definitely felt like a salmon struggling upstream against the current. I was thrust into a regular classroom with a regular education teacher without any supports. The teacher expected me to be an unwelcome and disruptive addition to her classroom and I lived up (or down) to her expectations. There were advantages

and disadvantages to being one of the first children to be included in regular classrooms.

There were no supports within the school other than a visit once a week with the school social worker. I looked forward to my once a week checkers game as a brief refuge from a classroom where I did not feel welcome. However, because there was not a "resource room" or contained classroom within the school, the teachers and administration had to learn to provide my supports on an individualized basis. I was not placed in a segregated setting within the school because one didn't exist at that point.

Toward the end of my rather lackluster tenure at Philips, the physical education teacher developed an adaptive P.E. program for myself and two other students with very mild cerebral palsy. He received a lot of recognition and I enjoyed being on television. Previously he had simply adapted the activities the rest of my class participated in so that I could be fully included in my gym class.

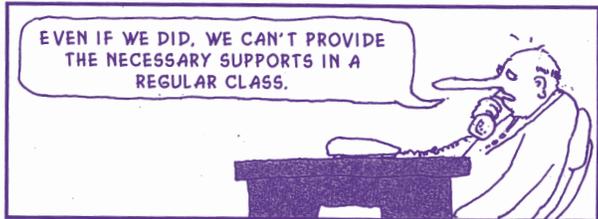
A fellow student and inclusion pioneer, Mimi, refused to participate in the video because she did not want to be seen as an object of pity or curiosity of the week on the

local news. It has taken years for me to recognize her lone act of courage, her refusal to be seen as a token, to have people view her as different and treat her as someone in "special" education, rather than simply a 5th grader, no different from any other student attending Philips Elementary.

Inclusion has replaced the term mainstreaming but has taken on the image of "dumping." What was wrong when I was mainstreamed and the problems with Inclusion today are still the same. Parents, teachers and students are not given the supports and resources they need to succeed. I am not referring to students receiving special education services, I am referring to all students. Classrooms are overcrowded, teachers are overworked, parents do not feel welcome or are too overwhelmed to contribute to their children's classroom learning.

A school is part of the community. It should not be viewed only as an institution of learning, but as a resource in the community. If we can change our perspective on schools to see them as valuable community centers, providing welcoming environments and opportunities for nurturing the myriad talents and skills which our future leaders, employees, and contributing community members need to find belonging in our society. This has to happen in the neighborhood that children live in to allow life-long partnerships, friendships, and real relationships to develop naturally and

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**A DISTANT COUSIN OF PINOCCHIO
DISCOVERS HE HAS INHERITED ONE OF
HIS FAMILY'S RECESSIVE TRAITS.**

Source: "Flying by the Seat of Your Pants: More Absurdities and Realities of Special Education" by Michael F. Giangreco C 1999. Reprinted with permission. Available from: Peytral Publications, Inc. P.O. Box 1162 Minnetonka, MN 55345 www.peytral.com

flourish without our intervention. We must learn to recognize that all people have worth and value, we all yearn to belong, to become accepted and contribute our unique gifts to our communities and our society.

A student who is bused to a school based on accessibility or "special programs" found only at that school is an outsider even before the first day of school begins. This student has no sense of belonging to the neighborhood. This student does not participate in the same summertime activities, sports events, church ice cream socials, is not invited to the same birthday parties. This student does not belong to the school and the school social structure does not provide a sense of belonging. In many cases, segregated settings still exist within the schools that simply reinforce the idea of difference; inclusion at the table at the back of the cafeteria during "regular lunch periods" is not inclusion.

My daughter attends the closest school in our neighborhood that is wheelchair accessible so that I can actively participate in her education and attend school functions. Being raised by an "inclusionist," Jessa has a heightened awareness of how society negatively reinforces or celebrates differences. The first week of school we heard tales of students with mobility impairments having to sit on the blacktop because they couldn't use the playground. This year a brand new accessible playground has been built but is used by children with disabilities at different times than the rest of the children. The "different" children eat lunch early and have recess while the rest of the school is in the cafeteria. When my daughter began to ride the bus she noticed that as labeled students were assisted off of the bus they were pushed by paraprofessionals to a fence closest to a locked accessible entrance and "guarded" until the bell rang and then entered the school with no interaction with other kids. These are situations of separatism and segregation that are created by well-intentioned and misguided adults. The adults are providing examples of bad behavior that reinforce children's misconceptions about diversity and disability. This leads to a condition called "Psycho-Sclerosis", or hardening of the attitude; a term coined by famed T-shirt entrepreneur, Dan Wilkins of The Nth Degree (www.thenthdegree.com).

As a cynical optimist I usually believe that systems run things and don't necessarily reflect the needs, wants or desires of the persons they are serving. I recently became involved in a group called the Community Action Venture. We are approaching inclusion as a natural consequence of community building within schools and the neighborhoods surrounding them. Each school has a distinct culture. The culture arises from many unique factors: the ethnicity, socio-economic background, traditions, values and culture of the neighborhood surrounding the school, the neighborhood from which students in the school originate. We need to change the way we see our schools, we must get involved on the local level working within our own neighborhoods to build a supportive community for all children. This is inclusion at its finest, we must "teach inclusion" through natural supports and in natural settings so that society learns to embrace the true meaning of inclusion without realizing that they are being taught.

Julie Farrar-Kuhn
Program Assistant for the Colorado Developmental
Disabilities Planning Council

After the show

Got the suit,
Used but quite fine.
Yes.
Songs sung by my wonderful school friends
&
Dancing girls
Only made me love being one of the cast.
Last and first on the stage
Like the tourist I was
Seeing the city and helping put on the show.

David Thompson
April 4, 2001





What do You do for Fun? Staff Favorites

Books:

The Sweet Potato Queens' Book of Love, Jill Conner Browne, 1999, Three Rivers Press, New York, New York.

Places that Scare You, Pema Chodron, 2001, Shambala Press.

Prodigal Summer, Barbara Kingsolver, 2000.

The Bone Collector, Jeffrey Deaver.

Movies

Memento

Visit our website: <http://www.cdhs.state.co.us/opi/cddpc/index.htm>



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