

BETWEEN.....THE LINES

FALL 2006

COLORADO DEVELOPMENTAL DISABILITIES COUNCIL

COUNCIL UPDATES

Councils are federally funded to create system change via

- ❖ Legislative and policy change
- ❖ Funding cutting edge grants that reflect best practice and can be replicated statewide

The Colorado Developmental Disabilities Council has changed its structure of late to reflect its work and efforts at system change. The structural changes include the creation of the Five-Year Plan Committee that monitors all Council grants, as well as the Public Policy Committee that works on policy to reflect the Council priorities. In addition there exists a Multicultural Committee that promotes educational opportunities and outreach to communities of color. The former committees of the Council (Education, Employment and Self-Determination) were issue-specific and no longer exist. In addition, the Five-Year Plan Committee will issue Requests for Proposals for larger amounts of money than the Council has issued in the recent past in order to promote more focused system change. To that end, funds used to sponsor individuals to attend training events (EACH) and unsolicited grants are on hiatus.

The Colorado Developmental Disabilities Council has adopted its Five-Year Plan for 2007-2011

What is the Five-Year Plan and what does it mean to the citizens of Colorado? Put simply, it is the driving force behind Developmental Disabilities (DD) Councils across all states and territories, including our state. The plan includes a description of where the state stands in education, employment, economy, politics, health, as well as current priorities for the Colorado Council.

The Council's Five-Year Plan Committee's initial responsibility was to develop goals and objectives based on public input. The Committee sifted through information from focus groups, web and print surveys and phone interviews in its effort to develop goals and objectives within areas of emphasis based on local concerns and needs.

Issues of concern that were raised by Colorado citizens fell into three areas of emphasis that now guide the Council's Five-Year Plan:

Employment, Formal and Informal Community Supports, and Quality Assurance (self-advocacy and leadership development). Some of the concerns about employment for people with disabilities included lack of employment options, including supported employment, and effective transition planning from high school to adult life. As one individual stated: "I wish there was someplace or someone that a person could go to so that the 'less than perfect' person would not have to feel set apart...different; but would be able to find employment like any other person."

Concerns around community inclusion were about specific access issues such as lack

of accessible transportation, and lack of inclusive recreation and other community activities. Attitudinal barriers were also part of people's concerns about people with disabilities being included and active in their communities. People also expressed the importance of people with disabilities being involved in making decisions about their lives, and in being involved in decision-making bodies in their communities.

In October 2007, Colorado will begin the implementation of the new plan that was approved by the Council on January 25, 2006. The new plan will be the focus of all Council work; grant dollars and policy efforts in the three priority areas. The Council will soon be issuing a Request for Proposals (RFP), offering a total of \$500,000, to be granted in amounts from \$100,000 to \$200,000, to projects that address the goals of the new Five-Year Plan 2007-2011. Please watch for the announcement of the release of the RFP and the dates and locations of regional technical assistance sessions.

The plan is really your plan and it will take concerted efforts by all partners for us to be successful. We would like to issue an invitation to anyone interested in participating in the Five-Year Plan Committee. Any input is welcome and appreciated. For a schedule of meetings or to obtain copies of the Plan, **please check on the CDDC website www.coddc.org or call the Council offices 720- 941-0176.**

Mary Russell, Council member from Alamosa, and Chairperson for the Five-Year Plan Committee



**Colorado Developmental
Disabilities Council**
3401 Quebec St., #6009
Denver, Colorado 80207
(720) 941-0176
cddpc.email@state.co.us
www.coddc.org

Council Members:

- Irene Aguilar—Denver
- Bill Baesman—Greenwood Village
- Bruce Cline—Denver
- Todd Coffey—Denver
- Linda Dunn—Denver
- Eileen Forlenza—Denver
- Penny Gonnella—Denver
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- Karmen Kelly—Fort Collins
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Three Scenes: Common Threads

valued role as a writer

*An Angel at My Table** is an autobiographical work by Janet Frame, who lived and wrote in New Zealand. Ms. Frame attended college to become an elementary school teacher yet had a strong interest in writing prose. Through a number of very circumstantial events, she eventually was in and out of mental institutions, yet maintained her writing. The narrative takes the reader to many places most of us never experience, with a direct presentation of historical events and little interpretation.

For example, the convenience treatment of the day was the use of the leucotomy (pre-frontal lobotomy). Janet had been promised to be put on the list for this procedure as the nurses indicated that she could become normal and then go work in town. As her name came closer to the top of the list for the leucotomy, the superintendent, who rarely spoke to any of the inmates, pulled Janet aside to talk. As he pointed to his newspaper, he stated, **“Have you seen tonight’s Star? You’ve won the Hubert Church Award for prose, for The Lagoon. I’ve decided you should stay as you are.** I don’t want you changed.” Janet’s life publicly turned at just that second as she achieved the valued status of a published writer. Instead of being treated by leucotomy, she was treated as a person of worth in an undiscovered role she had actually experienced all of her adult life, as a writer, not as an inmate, patient, or client. Her social role had changed from a space holder in an institution, to that of a valued and eccentric writer.

Janet clearly thanks the publisher for many things in her life.

Devalued Role as a supported employment client

Raymond Lemay **, a service provider in Ontario, related the following scenario regarding a conference presentation he witnessed. A panel of

Supported Employment providers bemoaned the fact that vendors at a flea market had not welcomed a person they worked with to set up an arts and crafts kiosk. The individual was

excluded from social events as well as business meetings, while the supported employment staff was always personally invited to participate. Upon closer exploration, it became clear that there was no fit between the identity of the person receiving services and his job as vendor nor was there any bridge put into place for the other vendors to interact in a reciprocal manner. In other words, because other people could not recognize this individual as a business owner, there was only superficial ‘role-playing’ occurring. The individual was merely space holding.

The situation did not reflect any individualization, authenticity, or reciprocity between the employees. The person owning the kiosk had no role as a business owner or artist. His role was as a consumer of services and a client.

By definition, reciprocity demands “a relation of mutual dependence or action or influence” (www.onelook.com). When individuals with disabilities participate at work, or anywhere else for that matter, it is essential to recognize a clear meaning to their presence, the task, and their contribution. In addition, to create mutual dependence it is just as critical to recognize both the reception and the contribution of co-workers.

Early Childhood Reciprocity

Morton Gernsbacher, at the University of Wisconsin in Madison, reflects on a 1992 study in which three typical preschoolers were taught to prompt three other children who had labels of disability.



I don't want you changed." Janet's life publicly turned at just that second as she achieved the valued status of a published writer. Instead of being treated by leucotomy, she was treated as a person of worth in an undiscovered role she had actually experienced all of her adult life, as a writer, not as an inmate, patient, or client.

When the typical preschoolers were taught to respond to the interaction that the preschoolers with labels initiated, the preschoolers with labels responded more often.

The typical preschoolers were told to **1)** wait for the other child to ask for a toy, **2)** ask the child to say the name of the toy, **3)** then give the toy to the labeled child when he used the correct name, and finally to **4)** praise the correct answer. None of the labeled children, despite the intense social skills training, maintained or reciprocated the initiation of this interaction with their typical peers. The supposition of Dr. Gernsbacher is that this is due to the fact that the interactions were not reciprocal—they were weighted one way (not mutually beneficial) and one of the parties was in a dominant position. In other words, there was no meaning to the interaction for either party or no rationale for the interaction to exist or continue existing—another space holding series of interactions.

A reverse and positive outcome occurred when researchers taught four typical preschoolers to either initiate interaction with three preschoolers labeled with autism or to respond to the interactions initiated, i.e. to be reciprocal. Which intervention had lasting influence on the social interactions of the preschoolers with labels? When the typical preschoolers were taught to respond to the interaction that the preschoolers with labels initiated, the preschoolers with labels responded more often. In other words, when the typical preschoolers behaved reciprocally, the preschoolers with labels responded more positively.

This finding seems self-evident. However, if one begins to apply the notion to actual practice, it appears to be very foreign. It is the rare occurrence in which a person labeled with disability is treated in a reciprocal manner rather than in a benevolent or charitable manner (or worse). Valued roles in work, living circumstances, or school are not achievable without reciprocity and a capacity to discover the individual beyond their label.

Common threads of isolation

With some capacity to generalize, one can connect the dots between the three scenarios above. The institutional experiences of Janet Frame in New Zealand in the 1940's, the supported employment worker at his kiosk in the 1990's, as well as the preschool students cited in studies, all include a lack of validation of a social role as discovered in a reciprocal human interaction. In other words, there is a lack of awareness or acknowledgement of the individuals' gifts, contributions, and personhood. No one in the environment has taken time to follow the individual toward his or her personal interests; rather an agenda has been imposed. The person is filling a slot in a disconnected service system. Despite the preponderance of the word "individual" in human service language, funding, and planning, the above circumstances would not have existed had true individualization and reciprocity been present. Had there been opportunity for expression of individuality on behalf of the persons with labels and receptivity from others, roles would have been created naturally. Janet Frame would have not been institutionalized at length, but would have realized her dream much earlier in life. The kiosk owner would be in a job that matched his interests in the role of co-worker. The preschool students from the first scenario would be playing with puppets or play dough, rather than being recipients of superficial one-way prompts.

*Frame, Janet, *An Angel At My Table*, George Braziller Publishing, New York, 1984

** Lemay, Ramond, *Social Role Valorization Insights Into the Social Integration Conundrum, Mental Retardation*, Volume 44, 1:1-12, February 2006

*** Gernsbacher, M. A., (2006). Toward a behavior of reciprocity. *Journal of Developmental Processes*, 139-152.

Money Musing\$

The number of jobs in the U.S. that pay less than a poverty-level income: **1 in 4**
www.povertyinamerica.psu.edu/2005/07/

The percentage of people in sheltered workshops in the U.S. who move into competitive employment in any given year: **3.5**
www.accessiblesociety.org/topics/economics-employment/shelteredwksps.html, 2002

State that has a law that exempts purchases made from sheltered workshops from competitive purchasing procedures: **Montana**
Mont Code Ann. §18-5-103, September 2004

State in which pawnshop owners noted that more people were pawning their belongings in order to buy gas: **Texas**
CBS11TV.com, April 2006

Percent of the U.S. population living below the poverty line: **13**
Income, Poverty and Health Insurance Coverage in the United States: 2004,
www.census.gov/prod/2004pubs/p60-226.pdf

Percent of the current housing programs for low-income people with disabilities this Administration proposes to cut: **50**
Budget of the United States Government, 2007

Percentage of Americans living below the poverty level who voted in the 2000 presidential election: **38**
Committee for Community Change, Washington

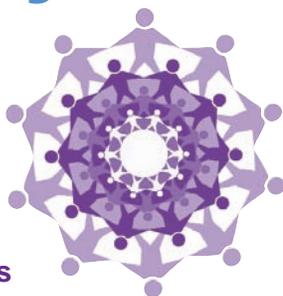
Percentage of Americans living at twice the poverty level who voted: **68**
Committee for Community Change, Washington

Ratio of the number of poor Americans living in cities to the number who live in suburbs: **21:20**
Harper's Research, December 2004



Let's Go For It—Community

Stacie was so proud to be a bridesmaid in her roommate's wedding. John never misses a day of work at the insurance company because he likes to eat lunch with his co-workers. Mary loves to pass out water at the walk-a-thon fundraiser as a member of the Lions Club. **This is community! What fun!** More



people with disabilities should have these community experiences. Most people want these opportunities in their own lives. As The Arc of Colorado & Visions for Independent Living traveled across Colorado giving presentations on self-determination, we heard from over 2,000 people with developmental disabilities, family members and providers. People are enthusiastic about being more involved in every aspect of community, but they always ask the same question: **“How do we begin?”**

To provide an answer, The Arc and Visions spent over a year developing the new *Vision Community Life Plan*, which is a completely new approach to person-centered-planning. Many of us get stuck in a “disability box” and this Life Plan gives us an opening to think outside the box, and looks at all aspects of community life. Our premise is:

The community is ready! We just need to find them.

The community is willing! We just need to ask them.

The community is able! We just need to involve them.

How does the *Vision Community Life Plan* work?

- ❖ A Facilitator oversees the entire process from beginning to end.
- ❖ The Life Plan covers four areas: Community Life, Community Employment, Community Activities and Community Friends. Individuals may choose any or all of these areas, depending on their interests.
- ❖ Individuals know best what they want, so they create their own Life Plan with the help of family or friends, if needed. To do this, the individual completes a Life Plan questionnaire that offers hundreds of choices and ideas, simply putting a checkmark next to each choice. This can be done in less than an hour.

- ❖ The individual invites community people and others to form a Network. Each Network member reviews the individual's Life Plan and starts thinking about how to make it a reality.
- ❖ The individual, Network members and facilitator join together at an Action Meeting to create solutions for the choices specified by the individual in the Life Plan. At the close of the meeting, all participants agree on the next steps to take.
- ❖ The Network members then explore, investigate and seek out opportunities available in the community.
- ❖ The Facilitator follows-up and supports the Network over the next six months to make sure there is a successful completion.
- ❖ Finally, the Life Plan is considered a success when the individual is involved in at least one aspect of community life.

Let me share the story of the first *Vision Community Life Plan*. Kara is an outstanding young woman who has many dreams and goals. She just wants a chance. Kara lives with her parents in the mountains, does not presently have a job and most of her social activities are with other people with disabilities. When I talked to the family, they were about to embark on seeking opportunities and thought that the *Vision Community Life Plan* would be a great way to get started. They completed the life plan questionnaire together, which helped give them insight as to what Kara wanted.

At the same time, they started thinking of community people they wanted to invite into the Network. They were very methodical about the people they chose—some knew Kara very well, some were acquaintances but were very involved in the community and would know resources, and some were providers. It was a very nice blend. All of the Network members received Kara's Life Plan before the Action Meeting so they could begin to formulate ideas and possibly come up with some answers.

The Action Meeting was so full of energy!

Kara's parents called it an “old-fashioned barn-raising” and the Network members were impressed with the excellent interchange of ideas, the teamwork, the “great energy making it easy to join in” and the “new ideas I would have never thought of.” Consequently, the Network offered ideas for a roommate, different community activities for Kara to get involved in, and several great employment suggestions.



In fact, there were too many to focus on all at once so we had to prioritize. For every idea that was suggested, each Network member was asked to pursue their contacts. Because each person is only taking one or two pieces of the action, it is not overwhelming for any one person. **It's great teamwork!**

The most exciting idea that came out of the Action Meeting was self-employment for Kara. To preface, Kara's mother was in a knitting group at a local hospital and Kara would come along just to socialize. Eventually, Kara started making scarves with the group. At the Action Meeting, Mary, a Network member, informed the group that Kara loves making

scarves and maybe she could have her own business. Well, it didn't stop there. Mary and Kara, as friends, investigated the idea of selling scarves. They went looking for material, they designed a label to put in each scarf, and they met with Mary's contact at her consignment shop. The contact was so impressed with Kara that she not only agreed to let Kara sell her scarves, but also offered to give her 100% of the profit, instead of the usual 50%. And it continues to move forward. Another Network member helped coordinate Kara selling her scarves at a booth at an upcoming community conference.

Kara's life is exploding with new and exciting changes happening all the time. Kara is just taking one piece at a time. But there is no doubt that Kara has a new Network of community friends who now know her, have new expectations for her, and will be there for her now and in the future.

Besides the individual being the focal point of the process, the facilitator is there to coordinate and keep the action going until there is completion. The Network members definitely are the key distinction of this Life Plan. They bring their expertise, their contacts and their resources. But beyond that, they are honored to be asked, they feel important for what they can contribute, and they feel good when they come up with a solution. Why shouldn't we let that happen? They have a right to be included with people with developmental disabilities and we should help that to materialize. To summarize, one Network member wrote, **"This is very exciting. I wish I had a life plan."**

If you want it, you can have it too. Just contact Nancy Baesman at 303-779-0909 (Denver) or 1-888-755-5484 (outside area).

Nancy Baesman, Visions for Independent Living

The contact was so impressed with Kara that she not only agreed to let Kara sell her scarves, but also offered to give her 100% of the profit, instead of the usual 50%.

Sheltered Work: Is It Stuck In Time?

The following is a synopsis of a recent article in the July 16, 2006 edition of the Oregonian, by Jeff Kossoff and Bryan Denson. The article, one in a series focusing on more than 20 sheltered workshops in seven states and the District of Columbia, provided insight into the fundamental systemic problem of sheltered work. Nationwide, there are close to 3,000 sheltered workshops, and they have resisted two decades of reform, including mandates from Congress, the US Supreme Court and the Bush administration to more fully integrate people into everyday life. This is in spite of the long-term work that has occurred to provide all students access to the regular curriculum in public schools and to move people from institutions into the community.

According to Tom Nerney, Director of the Center for Self-Determination, "There's a growing consensus that this [funding for sheltered workshops] is not a good use of public money." Supported Employment has shown that with the right supports, even workers with the most significant needs for support can make it in a real job, turning service recipients into true taxpaying members of society. The end result is a saving to all taxpayers in the long run.

Since the 1980's Supported Employment has benefited thousands. There is a broad acceptance among social scientists that putting people with disabilities in outside jobs enriches them and the rest of society. Unfortunately, this shift to Supported



Employment has stalled in recent years. Reformers say a mix of financial disincentives, institutional inertia, and failed leadership is to blame for perpetuating workshops, which is seen as a long-festering civil rights issue.

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How to Avoid Being Roadkill on the Road to Transition

By Katherine Carol

My back is a little stiff this morning. Sleeping on my daughter Mikelle's couch has that effect. It has been a week since I have slept in my own bed and I am not sure when I will lay my head once again on my own pillow.

The calendar seems to have picked up the electronic pace of the digital world as Mikelle leaps towards her 23rd birthday. Her life moves forward at 21st century speed while her systems of support crawl out of the 20th century.

Mikelle graduated in 2004 as an outstanding senior at East High School in Denver, Colorado. Mikelle, her team at school and I worked hard to develop a solid transition plan to follow graduation. We had our challenges, particularly with having five vocational rehabilitation counselors in three years while that system was going through major changes in our state. All the counselors had good intentions, but each was dancing the slow dance of catch-up. **And, everyone had to catch the vision Mikelle had for her life, which was to not just have a typical life, but an exceptional one**—one that was based on prosperity, not poverty. Too many times we accept poverty as an implied goal during transition. I can't say I have ever seen a goal on a transition plan that addresses getting people out of poverty. It is assumed—wrongly—that you have to be poor to get certain services. With Social Security work incentives like PASS Plans and strategies for developing small businesses, poverty no longer needs to be assumed.

My expectation for Mikelle, despite the limitations of significant cerebral palsy, and the use of a wheelchair and augmentative communication, is that she has to earn a living and could and should get the good stuff in life. Fortunately, she assumes that as well.

During school she was fully integrated into regular classrooms, and quickly developed friendships with other students. By the time Mikelle graduated she had had four jobs, two of them paying at least \$100 per hour and two of them paying well over minimum wage. The high-paying jobs were contract jobs, but still set the expectation that she could earn good money. The others were summer jobs. We used extended school-year dollars in partnership with some limited support from vocational rehabilitation to pay for a job coach during the summer. Summer job development was a cooperative venture between friends, family, and the school.

To have a chance at accomplishing real transition into adulthood—the kind where young adults actually own their own lives—requires vision, passion, focus, and most assuredly persistence. **And, the knowledge that your transition plans will most likely have to be changed and modified along the way**—many times. Sleeping on the couch is how my nights are spent at the moment. It reflects some of those changes and modifications that happen along the way. In reality, both Mikelle and I have needed a Plan B, Plan C, and now Plan D. We both have had to make adjustments and gain new insights into ourselves and the realities of successful transition.

One of Mikelle's goals on her transition plan was to live on her own. Talk about persistence; she reminded us constantly that she was determined to move out. We all thought it would be when she was 23 or 24 years old and that we would have a couple of years to make that happen. We signed her up for the Section 8 housing waiting list, figuring it would take several years, if not many years for her to obtain a voucher. Her voucher came up suddenly and we had 60 days to find her an apartment. We found her a two-



bedroom apartment so close to my home she can see it from her apartment window, plus it has a great view of downtown Denver. She has two bedrooms so she can have a roommate to provide overnight support and fill in a few hours a week.

I placed an ad on Craig's List, www.craigslist.org and we ended up interviewing five young women for the role of support person. We selected one and did reference checks, including a criminal background check. I stayed overnight for a week making sure they were comfortable, only to have it quickly become apparent that the arrangement was not going to work. Hence, the return to the couch. Mikelle would not even consider moving back home—I don't have cable!

So, what have we learned? As you let go and transition, have solid agreement between roommates and staff about expectations—they need to be written together and signed by all parties. No one is going to parent like you do, but they can bring new perspectives and learning experiences even if it looks like it failed. And be persistent and know that for your child's life to change, yours has to change as well. This way you will avoid being roadkill on the road to transition.

Katherine Carol is Mikelle's mother and owner of Tango Consulting, Denver, Colorado. She may be reached at kcarol@starnetdial.net, at 303/861-5256, or at www.tangoresults.com

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On-line Course

for People with Disabilities and Their Family Members

An excellent resource about self-determination can be found in the new on-line learning course, www.partnersinpolycymaking.com/living

Created by the **Minnesota Governor's Council on Developmental Disabilities** as a part of the Partners in Policymaking® on-line curriculum, the self-study course is designed to assist people with developmental disabilities, their family and friends explore four important elements that, together, can help them create a meaningful life: **Self-Determination, Family Support, Community Living and Assistive Technology**. In **The Freedom to Choose** module, participants clearly can learn about the history of personal choice, life planning and self-determination for people with disabilities. This exceptional curriculum has a glossary of terms and a wide arrangement of topics crucial in understanding self-determination ranging from "**Hard Choices, Big Decisions: Your Dream vs. the System's Dream**" to "**Who might benefit from Self-Determination.**"



Colorado Developmental
Disabilities Council
3401 Quebec st., #6009
Denver, Colorado 80207
M501000020

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