BETWEEN THE LINES



COLORADO DEVELOPMENTAL DISABILITIES COUNCIL

Spring 2013

The Long, Winding Road to Employment First

by Dale DiLeo

The following is taken from the February 2013 issue of APSE Connections and republished with permission.

Advocating for real jobs for people with significant disabilities has been around for over 30 years. Meeting APSE founder Wendy Wood as the organization was first coming together led me to join the APSE Board. Enamored with the mission, I soon started the first state chapter in New Hampshire, while I was a consultant working with the infamous state "system change" grants. (They never really significantly changed the system, unfortunately.) I became APSE's fourth president, and ended up serving on the board for nine years.

APSE has evolved and accomplished a great deal in very difficult circumstances. It has promoted training, shared new techniques, provided an annual conference for us to come together and collaborate, and recently has offered a path to certification for professionals.

Remarkably, though, despite all the advocacy and advancement, we haven't seen any improvement

over time in employment rates for the people whom we represent. The system has not really changed. What we have done is to painstakingly demonstrate a wonderful framework of what is possible and what can work in just about every region of the country.

I have witnessed many of you battling for individuals who were often dismissed as not being "feasible" for employment. This is no small feat for the many people whom we have helped realize job success. But this effort is not enough. It is one thing to succeed with some and show what can be done, and quite another to make it an everyday reality for all. Here's the task that remains, as I see it.

Highlight pay inequity where it exists—There is a disturbing pattern, especially in large agencies, of huge gaps among management, workers, and the wages of people in the employment programs they run. We must change a system that allows, and in some cases encourages, huge wage disparities. Studies have found that the average wage for private agency direct service staff was just over \$10 per hour in 2009, leading to excessive turn-over. Of course, staff turnover ultimately compromises services for people with disabilities. Meanwhile, in several recent media exposés, management staff of several large disability agencies have been found to earn six-figure salaries, been provided paid luxury cars, and even have extended high-paid positions for their family members.



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Lionel Llewellyn Administrative Assistant Of even more concern is that many of the workers with disabilities in sheltered workshops run by such agencies earn less than the federal minimum wage. (Currently about 420,000 workers with disabilities in the U.S. earn sub-mini-mum wage.) There are documented examples of workers earning pennies per hour, with this practice vigorously defended by disability professionals who opine that these individuals are at their maximum productivity.

Yet, the very notion that someone would believe that each person has some mythical fixed productivity level should be disturbing in our field. We know that productivity is related to many different conditions, including job match, level of support, accommodations provided, and so on. The very fact that productivity is primarily a function of our disability service capabilities is really the core foundation on which finding employment for people with job challenges is built. We must phase out special wage certificates that justify any subminimum wage, and stop using that approach to solve perceive low productivity. That simply is a cop-out.

Support self-determination—For self-determination to be successful, people with disabilities need meaningful experience, financial control, and information to exercise informed choices. We cannot allow the weak justification so often heard that a person "is happy where he/she is" to keep people in segregated programs, especially when the segregated program (or some token version of employment) is all the person has ever experienced.

Advocate for real inclusion and ending segregation—To believe you can obtain civil rights without acting to end segregation has been proven false with the long struggle for racial equality. It is the same in the disability field. Too many people verbalize how they are "pro-inclusion," but then do nothing to act on segregated programs and practices within

their own agencies. This is hypocrisy and it is often defended on the need to maintain a structure that people have just grown used to.

Fight discrimination—The broader context of the employment services we provide must move beyond the disability field's own current and limiting services, and into communities that still have stereotypes about autism, mental illness, and physical and intellectual disabilities. We must continue to educate and counter false perceptions and promote the successes that others did not expect. In addition, we must not only advocate with our words, but with our actions.

Continually develop quality—While we fight for job opportunities, we cannot lose focus on improving the quality of what we already do. This requires us to continually press for well-matched individualized employment with custom task sets and supports. It also means we must terminate group employment models.

We need to expect direct support workers to use effective and efficient supports that lead to self-sustaining job situations. This involves developing and providing good training that reflects evidence-based and respectful practices. Organizationally, we also need to pro-vide better career ladders and self-development opportunities for direct service professionals.

Demand respect—Globally, our field still uses labels and readiness training as a means to solving people's disabilities. This has been proven not only to be ineffective, but also harmful. We must end the use of disability labels—they stereotype employment possibilities and have no bearing on vocational success as compared to job match and support. The practice of people being kept out of job placement services because someone deems them "not ready for prime time" also needs to end. Finally, we must call out those agencies raising money based on pity or fear.

(Disclaimer)

The views expressed by authors in Between the Lines, the quarterly newsletter of the Colorado Developmental Disabilities Council, are not necessarily those of the Council, its individual members or the staff. Letters to the Editor are encouraged, as are requests for correction of factual information. Please direct such to the newsletter editor at marna.ares@state.co.us.





Summary

The crux of all these issues, as I now see it from the lens of a 30-year history, is that control of employment still remains with too many large provider agencies that have no impetus for change, face no competition, and continue to protect historical models under the guise of "this is what people need."

When the norms act to *restrain* the lives of people, rather than enable them, then it becomes a matter of principle to speak

and act out against them. This is the true nature of "Employment First." We must not allow this to be just a phrase that will ring hollow if our core policies and attitudes do not change. Make Employment First real. Speak out when it isn't.

Dale DiLeo is a Disability Consultant at TRN, Inc.(https://trn-store. com). Advocate, speaker and author, Dale is Past President of APSE. His recent book, "Raymond's Room," focuses on ending the segregation of people with disabilities in community life. More of Dale's articles are on his blog at http://raymondsroom.blogspot.com.

New Medicaid Program to Boost Colorado's Economy

In February 2013 the Colorado Health Foundation released the results of their comprehensive study of the impact of the new Medicaid program in Colorado. The study projected the following economic and budgetary impacts for the state:

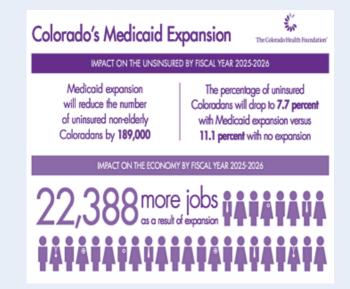
- 22,388 more jobs
- 189,000 fewer uninsured Coloradans
- A 3.4% drop in the number of uninsured
- \$4.4 billion in additional economic activity
- An annual increase of \$608 in household earnings as a result of the expansion
- \$133 million less in general fund appropriations because of full Medicaid expansion
- \$128 million more in tax revenue by 2025–2026

What we think and what we're doing:

This report shows that the decision to expand Medicaid is a smart thing for Colorado to do. Not only will 188,000 Coloradans be newly insured, but the expansion will also create 14,357 jobs in its first 18 months. CCHI is committed to seeing that the new Medicaid program is created in Colorado. We will also work to ensure that the new enrollees will have access to a robust benefit package so that they can get the care that they need when they need it.

What you can do:

- Check out the Colorado Health Foundation's report for yourself (http://www.coloradohealth.org/)
- Read other articles about the new Medicaid program
 - http://tinyurl.com/d4l7gbf
 - http://tinyurl.com/czylvzz
 - http://tinyurl.com/c728z8x















issue brief

Post-School Outcomes for Transitioning Youth with Developmental Disabilities Can we Predict Integrated Employment?

While strides have certainly been made, youth with disabilities continue to have less than desirable post-school outcomes (Newman, Wagner, Cameto, & Knokey, 2009; Wagner, Newman, Cameto, Levine & Garza, 2006). Although youth with developmental disabilities typically stay in school longer than their peers and often receive costly long-term funded supports as adults, national surveys document dismal employment outcomes for adults with developmental disabilities (Butterworth, Smith, Hall, Migliore & Winsor, 2008; Migliore & Butterworth, 2008).

author

Monica Simonsen

For example, Butterworth et al. (2008) found only 21.9% adults with developmental disabilities were engaged in integrated employment (defined as paid work in the community) while 78.1% were engaged in sheltered or non-work activities (e.g., recreation).

In a recent analysis of the National Longitudinal Transition Study–2 (NLTS-2) database, Carter, Austin and Trainor (in press) documented that 26% of transition-age youth with intellectual disabilities were working for pay (as reported by the youth and his/her family). However, the authors noted that 43% of those transition-age youth were working in jobs where most of their co-workers have disabilities. These jobs may have included enclaves, mobile crews, or sheltered work activities with sub-minimum wage or stipends paid by a community rehabilitation provider rather than directly from an employer. To date

these distinctions are not clearly captured in extant research. Moreover, there continues to be a need to accurately document the employment outcomes of transitioning youth with developmental disabilities and to identify those factors that influence the postsecondary attainment of direct hire jobs that pay above minimum wage.

This brief presents a condensed summary of a research study designed to more clearly define post-school employment outcomes, document the post-school outcomes for youth with developmental disabilities, and examine the predictors of successful integrated employment for youth with developmental disabilities, as defined by eligibility for long term funding support from state developmental disabilities agencies.







method

The term integrated employment has not been used consistently in research, policy, and practice however there is agreement that it refers to paid work in the community. Community rehabilitation providers that provide support to individuals with developmental disabilities have various models of integrated employment. For the purposes of this study individuals were categorized by the following outcomes.

Competitive Integrated Employment: individual works in community-based job with *typical peers* and is paid at least minimum wage *bv employer*.

Other Integrated Employment: individual works in a paid community job alongside other peers with disabilities (enclave/crew) and/or makes less than minimum wage.

Unpaid/Sheltered/Non-Work Activities: individual participates in unpaid community-based job or any facility-based work/non-work activities.

The study sought to identify those variables that best predict the various types of integrated employment outcomes (competitive and other). This was accomplished by surveying staff at 59 community rehabilitation providers across Maryland. The survey specifically asked them about youth with developmental disabilities who exited school in 2008. Surveys were completed on 338 youth who were out of school for approximately one and half years.

Respondents were asked to indicate the subjects' current employment status and provided information about the variables listed below. Each of these variables have been identified as potentially predictive of employment outcomes.

Variables Reported on Survey

- Race/ethnicity (Caucasian/non-Hispanic)
- · Male Gender
- Supplemental Security Income (SSI) recipient status
- Self-Management Skills
- Self-Determination Skills
- Community Mobility Skills
- Lives with Family

- Family Expressed
 Preference for Paid
 Community Employment
- · Family Involvement
- School Setting-Typical High School
- School Setting- Post-Secondary Education
- Work Experience- Unpaid
- · Work Experience- Stipend
- · Work Experience- Paid

findings

The study found that the majority of the subjects were placed in unpaid/sheltered/non-work (193 or 57.1%) rather than some type of integrated employment. Most notable is that only 14.2% of the youth were engaged in competitive integrated employment (see Table 1).

TABLE 1	No.	%
Unpaid/Sheltered/Non-Work	193	57.1%
Competitive Integrated Employment	48	14.2%
Other Integrated Employment	97	27.8%

The study further examined the relationship of the empirically-derived predictor variables and integrated employment. Table 2 shows the bivariate relationship.

Can we Predict Integrated Employment? Simonsen

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TABLE 2	X ²	R ²
Gender	2.10, p=.350	.01
Caucasian/Non-Hispanic race/ethnicity ^{ab}	8.43, p=.015	.03
Receives SSI®	13.88, p=.001	.05
Family involvement (rating scale)	4.48, p=.106	.02
Lives with family ^{ab}	9.86, p=.007	.03
Family expressed preference for integrated employment ^{ab}	60.58, p=.000	.19
Self-management skills (rating scale)ab	60.17, p=.000	.19
Self-determination skills (rating scale) ^{ab}	41.24, p=.000	.14
Community mobility skills (rating scale) ab	66.09, p=.000	.21
School setting		
Attended post-secondary programab	8.53, p=.014	.03
Attended typical high schoolab	10.64, p=.005	.04
Work experience		
Paid work during secondary school ^{ab}	27.77, p=.000	.09
Stipend work during secondary school	.08, p=.962	.00
Unpaid work during secondary school	.47, p=.789	.00
Has a VR Counselor ^a	8.34, p=.015	.03
Received VR funding prior to exiting school	.16, p=.924	.00
Community economy (unemployment rate) ^{ab}	7.05, p=.001	

All tests based on X2 with 2 df. Nagelkerke Pseudo R2 is analogous, but not identical to, the change in R² estimate from OLS Regression.

The variables found to have a significant relationship (p<.10) with integrated employment outcomes were further analyzed using a process called multinomial logistic regression. This process yielded a model of the variables that best predicted integrated employment outcomes for transition-aged youth with development disabilities. The following five variables in our model had a unique significant relationship with integrated employment.

- 1. Family member expressed preference for paid community employment (χ2=24.03, p<.001)
- 2. Paid work experience during school (χ2=9.68, p=.008)
- 3. Community mobility skills (χ 2=6.03, p=.049)
- 4. Self-management skills (χ 2=6.16, p=.046)
- 5. Race/ethnicity (χ 2=6.26, p=.044)

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^{*}Significant variables (p<.10)

^bVariables entered into the logistic regression testing model.

eVariables not entered into the logistic regression model because of missing data

^dCommunity economy was not assessed with the CRP survey; It was measured by the unemployment rate for the zip code in which the CRP was located.

The two most prominent variables that predicted integrated employment were family members who expressed a preference for paid community employment and paid work experience prior to exit from secondary school. These two variables were further analyzed to determine their odd ratio for predicating various types of integrated employment. The odds ratio is a way of comparing whether the probability of a certain event is the same for two groups. In this study, youth whose families expressed preference for integrated employment were 6.48 times more likely to achieve integrated competitive employment and 2.71 times as likely to achieve integrated other employment. Youth with previous paid work experiences were 4.53 times more likely to be engaged in integrated other employment.

summary

As made evident by this study transition age youth with developmental disabilities have not fully benefited from the paradigm shift toward integrated employment. The significant impact of families expressing a preference for integrated employment suggests a need for a substantial shift of resources and focus to the role of families in transition to employment planning. Long identified as an important component, the findings suggest that in addition to paid work experience, empowering families may be the most critical aspect of the transition planning process for students with developing disabilities who may require more logistical supports from their families than their peers with high incidence disabilities.

As previous research found (e.g., Fabian, 2007; Luecking & Fabian, 2000; Test et. al., 2009), this study strongly supports the value of paid work experience prior to exit from secondary education for youth with developmental disabilities. The study further distinguishes between paid and unpaid work experiences. The findings suggest that if integrated employment is the post-school goal, youth should be engage in authentic paid work experiences. While this study has expanded our understanding of the relationship between empirically-derived predictors and the various post-school outcomes for youth with developmental disabilities, it is important to continue to examine and clarify specific predictors of integrated employment. By doing so, secondary and transition practices can be aligned with other federal mandates for integrated opportunities.

references

Butterworth, J., Smith, F.A., Hall, A.C., Migliore, A., Winsor, J.E. (2008). StateData: The national report on employment services and outcomes, 2008. Boston, MA: The Institute of Community Inclusion (UCEDD).

Carter, E., Austin, D. & Trainor, A. (in press). Predictors of postschool employment outcomes for young adults with severe disabilities. Journal of Disability Policy Studies.

Fabian, E.S. (2007). Urban youth with disabilities: Factors affecting transition to employment. Rehabilitation Counseling Bulletin, 50(3), 130-138.

Luecking, R., & Fabian, E. (2000). Paid internships and employment success for youth in transition. Career Development for Exceptional Individuals, 23, 205–221.

Migliore, A., Mank, D., Grossi, T., & Rogan, P. (2007). Integrated employment or sheltered workshops: Preferences of adults with intellectual disabilities, their families, and staff. Journal of Vocational Rehabilitation, 26, 5-19.

Migliore, A. & Butterworth, J. (2008). Trends in outcomes of Vocational Rehabilitation Services serving adults with Developmental Disabilities: 1995-2005. Rehabilitation Counseling Bulletin, 52(1), 35-44.

Newman, L., Wagner, M., Cameto, R., & Knokey, A.-M. (2009). The post-high school outcomes of youth with disabilities up to 4 years after high school. A report of findings from the National Longitudinal Transition Study-2 (NLTS2) (NCSER 2009-3017). Menlo Park, CA: SRI International. Retrieved from www.nlts2.org/reports/2009_04/nlts2_report_2009_04_complete.pdf.

Test, D. W., Fowler, C. H., Richter, S. M., White, J., Mazzotti, V., Walker, A. R. Kortering, L. (2009). Evidence-based practices in secondary transition. Career Development for Exceptional Individuals, 32, 115-128.

Wagner, M., Newman, L., Cameto, R., Levine, P, & Garza, N. (2006). An overview of findings from wave 2 of the National Longitudinal Transition Study-2 (NLTS2). Menlo Park, CA: SRI International. Available at www.nlts2.org/reports/2006_08/nlts2_report_2006_08_complete.pdf.



Monica Simonsen, Ph.D., TransCen, Inc.

www.transitiontoemployment.org











Nomination forms are due by Monday, June 1st. Please fax or mail to CDDC. Colorado Developmental Disabilities Council 1120 Lincoln Street, Suite 706 • Denver, CO 80203-2117

720-941-0176 • fax: (720) 941-8490 • e-mail: cddpc.email@state.co.us

Education

Nomination Form for the 2013 Dan B. Davidson Excellence in **Inclusion Awards**

(You may also print this form on our website: www.coddc.org)

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 com-

Awards will be given to individuals, agencies or organizations that have

nstrated visior	nary practices—providing exemplary service and sup-
Defying the od- community. V agencies,	ds honor Dan B. Davidson, who died in 1996 at the age of 41. ds, Davidson had followed his dream of living independently in the We celebrate Dan's spirit and memory by recognizing individuals, and organizations that exemplify visionary practices regarding in the categories of education, employment, and community.
You	re Invited To The Dan B. Davidson
"Exce	llence In Inclusion". Awards!
T)	Vednesday, July 24, 2013
	5:30 - 8:00 p.m.
\mathcal{G}	Toliday Inn Denver East—Stapleton
3333 s	Quebec Street , Denver, Golorado 80207
banquet! Plea	e will only be able to accept the first 100 reservations for the ase R.S.V.P. ASAP! If you need an American Sign Language, or erpreter, please let us know no later than Monday, July 1, 2013.
720-9	Please—call us, email us, or fax us at: 941-0176 • cddpc.email@state.co.us • 720-941-8490.
When you respo	and about this complimentary banquet, please include the following:
Your name: _	;
if you wish to	also reserve places for your family member(s) or friend(s), please
indicate the o	other name(s):
Please list act	ecommodations that you or your party need (i.e. vegetarian/fish/
meat):	
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ports—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:

Employment

Community Life

_	category	ncil's annual celebration (this year, will receive an award honoring their
Name of Nominee:(Individual/Organization): Address:		
Phone	_ Email	
Nominated By:Address(es) of Nominator(s):		
Phone	_ Email	
Check award category for	nomina	ation:
Inclusion in Education: Individual Agency/Group/Organiza	tion	Inclusion in Employment: Individual Agency/Group/Organization
Inclusion in Community: Individual Agency/Group/Organiza	tion	
Biographical Sketch (Backgrouif necessary):		mation, attach additional sheets
Reason for nomination (includ	e additior	nal sheets if necessary):
References (if self-nominated)):	
1) NameAddressPhone		
2) NameAddress		

La fecha límite para los formularios de postulación es el 1 de junio. Favor de enviarlos por fax o correo a CDDC.

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Formulario de Postulación 2013 Premio Dan B. Davidson a la Excelencia en la Inclusión

(También puede imprimir el formulario en nuestro sitio de Internet: www.coddc.org)

El Premio Dan B. Davidson a la Excelencia en la Inclusión honra a Dan Davidson, cuya vida definió la inclusión. Dan desafió los pronósticos, dejó al lado los consejos de otros, y siguió su sueño de vivir de forma independiente en la comunidad.

En honor y reconocimiento del espíritu de Dan, el Colorado Developmental Disabilities Council reconoce las prácticas ejemplares de inclusión que apoyan a personas con discapacidades para que participen plenamente como miembros de su comunidad.

Los premios se darán a las personas, agencias u organizaciones que han demostrado prácticas visionarias—proporcionando servicio y apoyos ejemplares—para

Los premios honran a Dan B. Davidson, quien falleció en 1996 a los 41 años

de edad. Desafiando las probabilidades, Davidson siguió su sueño de vivir independientemente en la comunidad. Celebramos el espíritu y recuerdo de Dan al reconocer a individuos, agencias y organizaciones que ejemplifican las prácticas visionarias de la inclusión en las categorías de educación, empleo y comunidad. Lo Invitamos A Los Dremios Dan B. Davidson "Excelencia En La Inclusión" 24 de julio de 2013 5:30-8:00 p.m. Holiday Inn Denver East-Stapleton 3333 Quebec Street, Denver, Colorado 80207 Este año, ¡sólo aceptaremos a las primeras 100 reservaciones para el banquete! Por favor haga su reservación lo antes posible. Si necesitará un intérprete del lenguaje de señas o de español, por favor infórmenos a más tardar el, 1 de julio de 2013. Por favor llámenos, o envíenos un correo electrónico o un fax al: 720-941-0176 • cddpc.email@state.co.us • 720-941-8490 Cuando responda para este banquete de entrada gratis, incluya la siguiente información:

Si también desea hacer reservaciones para su familiar(es) o amigo(s), indique sus

Indique los arreglos especiales que usted o sus invitados necesiten (vegetariano/

_____y/o correo electrónico _

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pescado/carne):

 Educación 	Empleo	 Vida Comunitaria
· ·	remiados en cad	pración anual del Consejo (este a categoría recibirán un premio el de \$500.
Nombre del candidato: (Individuo/Organización): Dirección:		
Teléfono	_ Correo electró	nico
Postulado por: Dirección(es) de la persona(s		andidato:
teléfono	Correo electrór	iico
Marque la categoría del	premio para e	el candidato:
Inclusión en la Educación:		lusión en el Empleo:
☐ Individuo☐ Agencia/Grupo/Organiz		☐ Individuo ☐ Agencia/Grupo/Organización
Inclusión en la Comunidad: Individuo Agencia/Grupo/Organiz	ación	
Resumen biográfico (Anteced	entes, incluir hoja	as adicionales si hace falta):

personas con discapacidades que conducen a la inclusión como miembros activos

y valorados de sus comunidades. El Consejo reconocerá ejemplos destacados de

la inclusión en las siguientes categorías:

Teléfono _____

Dirección _____

Referencias (si se postula usted mismo):

1) Nombre ___

2) Nombre

Teléfono

Dirección

Razón de la postulación (incluir hojas adicionales si hace falta):

Sister Act Section







CANDO moves into its third year

by Corry Robinson, Executive Director of JFK Partners

The Colorado Collaborative on Autism and Neurodevelopmental Disabilities Options is an ad hoc committee of the Colorado Developmental Disabilities Council. Council members Carol Meredith and Corry Robinson co-chair this committee which is open to attendance by all interested individuals. CANDO meets quarterly on the Anschutz Medical Campus and may be attended in person or by phone. The next quarterly meeting is Friday June 14, 9 a.m.—Noon. The focus of this meeting is on services for adults with Autism Spectrum Disorders. Future meetings are Friday, September 13, 2013 and Friday, December 13, 2013.

The major focus of CANDO is to provide support and oversight to implementation of the strategic plan developed by the Colorado Autism Commission (http://tinyurl.com/cxyhjhl.) The Colorado Autism Commission Executive Summary can be found at http://tinyurl.com/d68naha.

The work of implementing of the 10-year strategic plan is concentrated among several committees, and also assisted through the support of a grant from the US Department of Human Services Maternal Child Health Bureau. These committees include: Data and Infrastructure; Screening and Diagnosis (across the life span); Early Intervention; Education; Medical and Mental Health Services; and Community Living. Participation by any interested in any of these committees is welcomed.

The quarterly meetings involve presentation on a specific topic and a featured presentation from a person with a developmental disability or parent of a person with a disability. Council member Mike Hoover gave a very moving presentation about how he has learned to manage the anxiety he feels. Mike's and his mother's (Donna Downing)

consistent participation in CANDO are an asset to the meetings.

At the December 2012 meeting we had a presentation from Dr. Joni Beasley from the University of New Hampshire. Dr. Beasley's presentation focused on The Center for START Services (Systemic, Therapeutic, Assessment, Respite and Treatment, http://www.centerforstartservices.com.) START is a crisis intervention, system-change model for people with co-occurring intellectual and/or developmental disabilities and psychiatric disorders. We are hoping to proceed with a statewide analysis of the capacity Colorado has across systems and what capacity would need to be developed to implement such an approach in Colorado. Currently we have no way of knowing the total number of people, children and adults in Colorado who are affected in this way, other than the anecdotal reports we receive about truly heart-wrenching experiences of spending several days in emergency rooms and then being sent home with no intervention. Development of capacity for such intervention has come to be a major focus of CANDO.

Through the funding for CASCADE/CANDO we are able to take CANDO efforts around the state for community stakeholder meetings. These community meetings are jointly sponsored through the CASCADE grant and the local community. In August 2012 we held the first of these meetings in Mesa County hosted by STRIVE (formerly Mesa Developmental Services). Approximately 60 people came together for a day-long meeting that identified community strengths and gaps regarding services and supports for persons with autism and other neurodevelopmental disabilities. Stakeholders included representation from medical, educational, developmental disabilities, mental health and social services systems, parents, individuals with disabilities, and advocates. Some of the outcomes from the meeting include plans for a conference and expansion of services.

Over the next six months we plan to hold similar meetings in other communities around the state including Colorado Springs, Glenwood Springs, Arapahoe County and northeast Colorado.







The CANDO website is up and running but needs work to make it easier to navigate. If you don't find the information you are looking for please feel free to contact me through

the JFK Partners website at www.jfkpartners.org. I look forward to hearing from you

.

Beth Will, a voice for community living

by Jennifer Shook, Advocate, The Legal Center

In Beth Will's 51 years, she has been a daughter, a sister, a girlfriend, a self-advocate, a person with an intellectual disability, a friend and a trail blazer for others. In the past 30 years she has received services through the local community centered board, living and working in her beloved community with as much independence as possible. She lived in her own apartment with her long-term boyfriend for six years until she became ill.

Beth was hospitalized in June 2011, diagnosed with renal failure and severe cellulitis. With care, her health improved and her physician placed her in Grace Health Care of Glenwood Springs, a nursing facility, to continue occupational and physical therapy to regain her strength. In August of that year, her physician documented that Beth was able to receive services in a group home setting. Beth continued to work on independent living skills with restorative therapy through the fall and winter while waiting for an opening in one of the community centered board group homes. In February 2012, Mountain Valley Developmental Services had an opening and requested home and community based services (HCBS) from the Colorado Division for Developmental Disabilities. The request was denied.

Beth was broken hearted. She was adamant that she wanted to live outside of the nursing facility and back in the community she so loved. The Legal Center staff attended meetings with the local community centered board and wrote letters in support of Beth receiving the resources she needed to leave the nursing home. Our letter to the Colorado Division for Developmental Disabilities stated that Ms. Will's situation was a clear violation of the integration mandate of the Americans with Disabilities Act (ADA). She met all the criteria of the U.S. Supreme Court's "Olmstead" decision that requires states to eliminate unnecessary segregation of persons with disabilities and to ensure that they receive services in the most integrated setting appropriate to their needs.

Several months later, Beth was finally awarded a resource slot by the Colorado Division of Developmental Disabilities. Nearly 14 months after moving into the nursing facility, she was finally going to be able to move back into the community. Beth's story is one of many. Individuals with intellectual disabilities and mental illness find themselves institutionalized in nursing facilities, often alone and away from their support system. Beth had a voice and made it clear to people she wanted to be in her community. However, so many individuals don't have a voice and no one has advocated for them until now.

The Legal Center's research has uncovered the disturbing fact that there are more individuals with mental illness or intellectual/developmental disabilities institutionalized in Colorado nursing homes than on the main campuses of the Regional Centers, the Colorado Mental Health Institute at Fort Logan, and the Colorado Mental Health Institute at Pueblo, combined. The Legal Center has initiated projects to identify these nursing home residents and determine if they wish to leave and live in the community. Reviewing data obtained from state agencies, we have found a total of 2,055 residents of whom 1,742 are diagnosed with a major mental illness, 275 with developmental disabilities, and 38 with both a major mental illness and a developmental disability. Of the individuals identified, 33 percent are 65 years old or younger.

In the past year, The Legal Center's Protection and Advocacy for People with Developmental Disabilities (PADD) program identified 51 residents ages 50 and under and began the huge task of visiting each one. That required visiting 33 nursing homes across the state and meeting with each individual on our list. In the Protection and Advocacy for Individuals with Mental Illness (PAIMI) program, staff began by targeting two nursing homes: Park Forrest in Westminster and Spearly Care Center in Denver. Through that process we have talked with eight individuals with developmental disabilities who clearly wish to move to a community setting (it was nine, but Beth was successful in moving) and seven individuals with mental illness who desire to live within their communities.

While Beth Will is enjoying her re-found life within her beloved community, she has blazed another trail for others who are institutionalized: "I want to help all the other people that are still in the nursing homes" she says. The Legal Center is very proud to have helped Beth and we look forward to giving a voice to those who cannot speak for themselves.







Community Concepts

How was Employment First established for people getting food assistance from federal programs in 1996? The Personal Responsibility and Work Opportunities Act of 1996 (http://www.colorado.gov/cs/Satellite/CDHS-SelfSuff/CBON/1251581773899)

The number of states that have an Employment First policy for people with disabilities (real jobs for real pay and benefits): 15 (http://www.apse.org, http://www.employmentfirst.net)

The number of workers with disabilities who are earning sub-minimum wage: 420,000 (https://trn-store.com)

Date that H.R. 831, Fair Wages for Workers with Disabilities Act of 2013, was introduced into the U.S. House of Representatives: February 26, 2013 (http://www.govtrack.us/congress/bills/113/hr831/text)

The number of communities where aging in place has evolved into aging in community: 17 (http://www.agingincommunity.com/)

Date the US Department of Human Services announced the creation of the Community Living Initiative: June 22, 2009 (http://www.hhs.gov/news/press/2009pres/06/20090622a.html)

Date Governor Hickenlooper announced the creation of the Office of Community Living: July 11, 2012 (http://tinyurl.com/c7tx3bp)



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