

NASHIA
Oct 2011

Promises and Perils of
community engagement
Janet M. Williams, MSW, PhD

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Imagine If...

- You paid \$500.00 for a room but didn't get room service.
- You had a roommate and it was someone you didn't know or particularly like.
- You called the front desk and were told it wasn't your turn for an answer.
- You had to WAIT until it was your turn for most anything you needed, including a cup of coffee, newspaper or turn in the bathroom.
- You had to ask permission to watch a favorite TV show, have a pop, make a phone call, or smoke a cigarette.

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Current reality in brain injury services

- We often look at problems and dysfunction
- We congregate people into services
- Often experts feel they know best
- Professionals serve, customers receive
- Money is spent on initial fixing, leaving little for lifelong support
- Outcomes are problem based
- Consumer is exempt from responsibility
- Consumers must earn their rights

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Imagine If...

- You lived in your own home, hated oatmeal but had to eat it every morning at 6am AND you hated getting up early.
- You had to EARN the right to take a walk in your neighborhood.
- You valued your privacy, but always had a roommate AND it was someone you didn't pick.
- You had to WAIT until it was your turn for most anything you needed, even the most basic of needs.
- You had to ask permission to watch a favorite TV show, have a pop, make a phone call, or smoke a cigarette.

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The result...

- Consumers are treated like commodities
- All actions and behaviors are measured
- A we/they perspective unfolds
- Promotes a “sick role”
- Suggests that the expert knows best
- Promotes and reinforces stereotypes

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10 Promises and Perils

- that keep people with brain injuries from community

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P&P one

The promise- Experts/ medical professionals know best

The peril- Experts/ medical professionals know best



P & P two

- The promise- We have learned a lot about brain injury in the past 30 years
- The peril- All services need to be specialized and brain injury is so “unique” that people need something different than the rest of the world

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P&P Three

- The notion of a “continuum of services”



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P&P Four

- Testing has become very specific and defined
- 4+4= sheltered workshop for you

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P&P Five

- The promise- You get to go home
- The peril- Living in the community is next to impossible and a second best alternative

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P&P Six

The promise- The system has amazing services.

The peril- You will be controlled as
Long as you are in the system.



P&P Seven

- The promise- People with brain injuries are capable of overcoming amazing obstacles.
- The peril- Denial is bad and too many people have “unrealistic expectations” and “inappropriate behavior”

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P&P Eight

- The promise- Research shows the more friends and social connections you have, the happier and healthier you will be.
- The peril- A group home is community based and a sheltered workshop is a job, keeping you from full community engagement.

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P&P Nine

- The promise- That everyone wants to be the way they were before the injury so we must fix people.
- The peril- Fixing becomes a fixation and you will never be good enough.

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P&P Ten

- The promise- The most expensive services are the best services.
- The peril- community based services become second best and more scarce.

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The \$265,000 behavior plan

- These are some things listed below that we are working on implementing to encourage Jeff to be med compliant:
- we will upgrade his cigarettes from Golden Harvest to a higher grade of cigs, like Marlboros. He would still contribute his weekly money (16.24) but the incentive would cover the rest. This would be a weekly incentive.
- In addition to the cigarettes, if he's med compliant for say, 2 consecutive wks, I will add a lunch or dinner outing to the restaurant of his choice.
- Finally, if Jeff is compliant for 4 weeks, I will take him shopping for a new outfit or something.

Along with this the counselor is working with the team to educate Jeff on the suggested medications. Please let me know if you have any questions.

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So really,

how are we doing?

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The revolution is here

- Consumer focus
- Choice
- Self determination

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Long term support

The shift from professional direction to personal direction

- When and how it is done is the greatest challenge in the field of brain injury

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Inclusion means

- Being at the table
- Being a part of the discourse
- Being respected for who you are, not held accountable for what others expect you to be
- Acknowledges that people may be different and pushes us to respect diversity

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Philosophical Principles

- People using services and families know themselves best
- All people have goals and aspirations -Our job is to assist in setting those goals and working toward those aspirations
- Services must be functional, have a purpose and take place in natural environments
- People using services have the right to supervise their own personal assistants
- All people have a place to contribute in the community- It is our job to assist in finding that place
- Support resources include natural supports, community supports and personal assistance services
- People must live in generic affordable housing within communities and neighborhoods
- The provision of support services is separate from housing- We do not own or operate property where consumers live.

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Principle One

People using services and families
know themselves best

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Principle Two

Services must promote self-sufficiency
and community membership

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Principle Three

People using services hire
and manage their personal assistants

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Principle Four

All people have a place to
contribute in the community-
It is our job to assist in finding
that place

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What about Bob?



- Lived in a nursing home for 13 years
- Moved to his own apartment on the head injury waiver using communityworks
- Now uses the physical disability waiver in the same home through communityworks
- Manages his own staff, calendar and payroll after learning those skills
- Used communityworks for case management, independent living skills and all therapies
- Now uses communityworks for IL Counseling and payroll services

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APOCALYPSE THEN
Memoir explores paranoia, pop culture in Kansas
Pulse 6A

SENIOR NIGHT
Sherron Collins prepares for final home game
Sports 1B



LAWRENCE
JOURNAL-WORLD

75 CENTS

TUESDAY • MARCH 2 • 2010

LJWorld.com

Sunny but cool



High: 41 Low: 17
Today's forecast, page 10B

INSIDE



Leno returns to late-night time slot

The "Tonight Show" has its old host back, and Jay Leno hopes he can just pick up where he left off last year. Page 9A

CHILE

Chaos uncontrolled in earthquake zone

Military troops are fighting an uphill battle to contain the looting and violence that has erupted since a massive earthquake struck over the weekend. Page 2A

"It can happen to anyone. We are all one car wreck away from Medicaid."

An escape from 'hell'

Home agency saved his life, but state's financial crisis puts program in jeopardy

By Karrey Britt
kbritt@ljworld.com

Bob Kania is happy to be in his own home. Just like you and me, the 44-year-old Lawrence resident enjoys playing games, joking with friends, eating good food, and cheering on his favorite team.

But for Kania, a paraplegic, none of it would be possible without the assistance of a home health agency. Instead, he would be in a nursing home — or what he describes as "hell."

•••
In 1985, at age 19, Kania suffered spinal cord and brain injuries during a motorcycle wreck in Leavenworth. He spent six months in a coma, and then 12 years in and out of



Emotion runs high at school forum

By George Diepenbrock
gdiepenbrock@ljworld.com

ONLINE: See the 6News report and more coverage of the school budget issue at LJWorld.com

Near the end of the Lawrence school board's budget hearing Monday night at Central Junior High, an audience member yelled out.

She asked everyone who didn't want board members to close schools to stand up. Nearly all of the 120



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Principle Six

All people have a place to contribute
in the community- It is our job to
assist in finding that place

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Finding a place in the community



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Principle Seven

Support resources include “natural supports,” community supports and personal assistance services

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Principle Eight

People must live in generic affordable housing within communities and neighborhoods

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Principle Nine

The provision of support services is separate from housing- We do not own or operate property where consumers live.

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Staff standards

- Do whatever it takes to be connected in the community...
- Work yourself out of a job so you have the benefit of working with more people
- Create a vision with the person of what they want their life to look like
- Uphold “nothing for me without me”
- Be the coach, consultant and support, not the boss or expert

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Social Capital

- Is the connectedness among and between people
- The more relationships people have in their lives the better their lives become...healthier, happier and live longer
- What is the average number of friendships for people without disabilities?

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Self Direction

- A law in the State of Kansas allowing people with disabilities to hire, train and supervise employees to provide the assistance needed to live in the community, even the tasks traditionally provided by a registered nurse.

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Background on the Traumatic Brain Injury waiver

- First brain injury waiver in the USA-implemented in 1991
- A rehabilitation waiver, time limit determined by ongoing progress
- Choice of institutional or community services to maintain cost comparison
- Average monthly cost \$3,400 per person
- Average annual savings \$39,000 per month per person when compared to institutional placement
- Overall goal is self sufficiency in the person's own home and community
- Service providers are independent living centers or home health agencies who meet criteria
- Consumers have full choice of agency and self direct option for personal assistants

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Services available on the Kansas brain injury waiver

- Case management
- TLS- transitional living...also known as independent living skills training (4 hours a day, 780 hours a year)
- Therapies- Physical, Occupational, Speech, Cognitive, Behavioral, Drug and Alcohol
- Personal Assistance- to supplement other services and can be 24 hours a day
- Personal Services- Durable medical and home modifications to a maximum of \$7,500 lifetime
- A person can receive services as long as s/he has goals and is making progress as defined by the person, staff and state

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Kansas Medicaid Home and Community Based waiver

- Ages 15-65
- Traumatically acquired, nondegenerative brain injury
- Medicaid eligible
- Score on Uniform Assessment Instrument
- Can benefit from independent living skills training

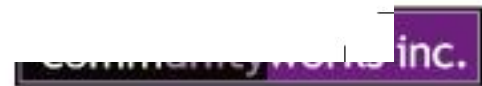
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Rehabilitation Therapies are provided by

The logo for Minds Matter LLC features a large, stylized letter 'M' on the left. The left vertical stroke of the 'M' is green, and the right vertical stroke is orange. To the right of the 'M', the words 'Minds' and 'Matter' are stacked vertically in a green, serif font. Below 'Matter' is the text 'LLC' in a smaller, green, sans-serif font. The logo is set against a white background with decorative orange and green curved lines and a horizontal green line passing through the text.

M Minds
Matter LLC

The logo for Community Works Inc. consists of the text 'community works inc.' in a white, lowercase, sans-serif font. The text is contained within a dark purple rectangular box with a thin white border.

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Creates positive environments by:

- Assisting people to set their own goals
- Setting up an array of services based on the person's goals and needs
- Using specific teaching techniques including: specific direction, consistency and repetition, foreshadowing/ pre-learning, honesty, humor, choice and control, plan, plan and plan
- Focusing on the tension created with the old self/ new self dilemma for both the person and family
- Using verbal, visual and physical prompts as accommodations rather than trying to fix a person
- Setting people up for success
- Allow the individual to lead decision-making and participate in staff training
- Get input from the individual on modifications and settings
- Partial participation/ Task breakdown
- Functional Tasks
- Meaning through stories and metaphors
- Natural consequences
- Creating a lifetime system in the person's own home and community

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Challenges to Families

- Yet another “new” approach
- Natural consequences and the associated fears

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Challenges to self advocates

- Trying things for the first time ever
- Another new idea
- Natural consequences and the associated fears

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Get a CLUE...

- **C**reate positive environments with control and choice
- **L**isten to the consumer and develop goals based on what you hear, not on what assessments reveal.
- **U**nderstand what is happening from the person's perspective
- **E**xpect that every day brings struggles, surprises and successes.

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Myths about Brain Injury

- Experts/ medical professionals know best
- All services need to be specialized
- The notion of a “continuum of services”
- Repeated testing is a good thing
- Living in the community is next to impossible and a second best alternative
- People with brain injuries need someone to tell them what to do
- Denial is bad and too many people have “unrealistic expectations” and “inappropriate behavior”
- People are now incapable until they prove they are capable...and need to earn the right to do things
- That everyone wants to be the way they were before the injury

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Realities about the experience of brain injury

- There is a great disparity between who the person was ...and is now
- There are family messages that “we want you back the way you were”
- Societal messages that it is not okay to have a disability
- Personal messages that “ I am not okay the way I am”
- Major changes in economic status ie, work, living, relationships etc
- During recovery, and often forever, a person is assumed incapable until proven capable

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The state of Kansas statistics

Year	Average # of People on HCBS/TBI Waiver (monthly)	Avg. cost per person per month for people on waiver	Avg. # of people in TBI rehab facilities (monthly)	Avg. cost per person per month people in TBI rehab facilities
2005	151	\$3,351.00		\$23,282.00
2006	167	3,096.00		\$22,576.00
2007	183	\$3,703.00		\$26,142.00
2008	196	\$3,690.00	27	\$26,253.00
2009	243	\$3,505.00	30	\$23,543.00
2010	323	\$3,196.00	39	\$21,550.00



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Per person spending July, August, Sept, Oct and Nov 2010

Month	Average # of People on HCBS/TBI Waiver	Total spent on HCBS for the month	Avg. # of people in TBI rehab facilities	Avg. cost per person per month people in TBI rehab facilities
July	336	879,000	45	925,000.00
August	321	921,000	41	709,000
September	351	1,316,000	37	1,054,000
October	353	987,549	32	633,458
November	326	901,950	38	726,575

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Communityworksinc by the numbers

- Started in 1991
- 31 case managers
- 45 people teaching independent living skills
- 538 consumers served in September
 - 143 tbi waiver
 - 143 pd waiver
 - Remainder- money follows, employment, frail elder, private etc.
- Preparing for managed care
 - Care coordination
 - Assessment
 - Who knows what it looks like?

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Do you have a brain injury?

No, I'm single

- What difference does a head injury really make when someone wants to live in the community?

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Communityworksinc and Minds Matter LLC

Create positive environments by:

- Assisting people to set their own goals
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