Monday, July 13, 1998

1) Pamela got a strange call this morning from the lady in Chicago saying Lex was not going, but Pamela was coming. Needs to talk to you asap.

2) Blake Williams called Friday. (604) 660-7890 (direct) or (604) 671-8742 Called to see if you knew Dr. Mark Taylor, of San Antonio, who is the president of the American Academy of Disability Evaluating Physicians. He is involved in some workers comp changes, particularly Special House Bill 2055 in 1993 and 1994. He was appointed by Lt. Gov. Bob Bullock and was head of the task force on Workers Comp of Baexer (sp?) County Medical Society. He suddenly appeared in BC and was just checking him out.

3) Sharon Masling in Tom Harkin's office called (202) 224-3254 to see if you got some funding to come to the meeting.

4) Damita (512) 463-2330; Bob Lanier wants to invite you to a meeting tomorrow, Tuesday, July 14 at 10:00 at UH. One of the issues is affirmative action and contracting with the State. She will fax us info.

5) Pamela called. She is now going to the Chicago meeting--after I mentioned that they were planning to pay your expenses, she read her letter and was also invited and will pay her expenses. She leaves early Wednesday morning and back on Thursday night and in the office on Friday.

She was asking about the RTC meeting next week. You, June and Pamela were supposed to meet about the T-1 project--are you planning on doing that on Monday when Bob Michaels is here (12 noon and on)? She needs to go to the Valley next week and is trying to figure out which day is best. She called back--she's leaving Tuesday for McAllen.

Her new home phone number is (713) 779-3380

6) Katie Koenig called. 898-2529 She was referred to you by the Chronicle. She is disabled and had a terrible thing happen to her. She called the Chronicle and they weren't even interested--"sorry, but those kinds of things happen to normal people all the time--it's just not convenient." She's tried everything, Dept. Of Justice, lawyers--nobody wants to help.

Rehabilitation Research and Training Center On Aging and Disability

Rancho Los Amigos Medical Center • University of Southern California
7601 E. Imperial Hwy., Downey, California 90242 • (562) 401-7402 • FAX (562) 401-7011

June 26, 1998

Lex Frieden
ILRU Research and Training Center
on Independent Living at TIRR
The Institute for Rehabilitation and Research
Independent Living Research Utilization
1333 Moursund Avenue
Houston, TX 77030

Dear Dr. Frieden:

We are pleased to give you this complementary copy of a 30 minute videotape entitled, ***Serving on Research Advisory Boards: Practical Tips for Achieving Maximum Impact.***

As you know NIDRR has been encouraging researchers to include consumers in the planning and implementation of research as well as in the dissemination of results. Many consumers find themselves uncertain about their role in the process. This videotape is designed to clarify that role and to prepare the consumer for meaningful participation. It is divided into two segments: the first describes methods for effective participation and the second describes the purpose of research.

We hope you will show the video to prospective consumer advisors, current consumer advisors, and to the researchers. Open captioned tapes are also available. Please let us know if you require one.

Feed back is encouraged and welcomed. You can contact us by writing to 7601 E. Imperial Highway, 800 West Annex, Downey, CA. 90242 or by email at: mosqueda @ uci.edu.

Sincerely,

Laura Mosqueda MD

Laura Mosqueda, M.D.
Training Director

LM:jg

encl.

Supported by the National Institute on Disability and Rehabilitation Research

Friday, June 19, 1998

Lex:

1) Jim Krause, Shepherd in Atlanta (404) 352-2677 called yesterday at 6:20 pm. Mike is out of town. Will answer any questions you have about the professional advisory panel. He'll call again Friday.

2) ~~Roland called to chat. (937) 237-8360.~~

R 3) Virgil called. Please "call when you get an opportunity." 942-6164.

4) William D. Clark
Senior Research ~~Analyst~~ Analyst
HCFA
(410) 786-1484
800-725-3341 - Coop in Medford

Lex

ilru

Time Spent : Continental:

- Meeting with Staci at airport - Lex, Joe, Richard, Laurie
- 1½ days training for cont. staff Wendy, Laurie, Lex, Joe (March + April)
- 2 days training for Cont. Supervisors Wendy, Lex? (May)
- + your time

Do you want to include time spent on video?

lsr

2323 S. SHEPHERD•SUITE 1000•HOUSTON, TX 77019•(713) 520-0232, 520-5136 (TTY)
(713) 520-5785 (FAX)

WORLD CLASS SUPERVISORS
Customers with Disabilities Breakout

INTRODUCTION:
10 minutes

Read Bad Letter (Wheelchair Service or Wheelchair used as luggage cart)

Introduce Co-facilitators

- Who they are.
- What they do.
- Why are they here.

DIFFICULT SITUATION:
25 minutes

Divide class into five groups.

Have each group complete a flipchart with the following:

- Top three difficult situations (relating to customers with disabilities).
- Why are they difficult?
- How do you feel when it happens?
- What have you done to over come the situation?

Discussion around the situations, what can we do to help, how has someone else dealt with it, how is the law involved.

JEOPARDY:
20 minutes

Divide class into three groups.

- One participant from each group will come up to the playing board.
- One person will choose a question (based on color and point value).
- Question is read the first person to ring in gets to answer the question.
- If no one knows the answer they can go back to their group to get the answer, then ring in.
- High score wins, however the entire class gets a prize.

(20 Jeopardy questions about DOT Part 382, Oxygen, wheelchair, assistive devices, service animals, etc.)

TRUE/FALSE:
25 minutes

Handout one card (index cards with a statement being true or false) to each participant.

- Their "mission" is to determine which statements are true or false. Explain they are free to use any method to accomplish the task.
- When group is finished have each card read and obtain the groups opinion.
- Give feedback about each card.

MEET THE PROS:
20 minutes

Hold a press conference.

The class is the press.

Co-facilitators are the Pros.

CLOSE:
10 minutes

Read good letter.

BAD LETTER

We recently took flight #604 from Orlando, Florida to Newark Airport on May 3, 1997. Unfortunately, our flight was delayed for two hours because of weather conditions at Newark. Due to the fact that my daughter is handicapped and wheelchair bound, we were one of the first people to enter the aircraft. We advised the attendant that we needed her wheelchair when we departed the flight due to her handicap. We were advised that her chair would be waiting for her when we landed.

Upon our arrival in Newark, we waited to get off the plane. I checked for the wheelchair and it was not there. I had to physically carry my nine year old daughter off the plane and all the way down into the gate area. At that time I met my wife who was frantically arguing with one of the attendants trying to call her attention to the men on the ground who were unloading luggage off the plane.

To my total amazement, I turned and looked out the window to see the cargo person getting all the strollers and equipment off the plane, using my daughter's wheelchair to cart them to the steps. I had to stand there for 25 minutes with my daughter in my arms until this man was finished using the chair to push everything back and forth so he did not have to carry it, he just kept loading everything into the chair.

This was absolutely unacceptable to us and I feel that your employees should be made more aware of the needs of handicapped people. If I were capable of carrying my daughter back and forth, we wouldn't need the wheelchair. We did not even receive an apology for our inconvenience.

This experience has most definitely soured me on Continental Airlines. I cannot believe that such a large company can appear so inept. It was not bad enough that on our flight #459 to Orlando, Florida a piece of our luggage was destroyed and had to be replaced but to be left without a wheelchair is totally irresponsible.

I hope you will make some needed changes in the future.

JEOPARDY QUESTIONS

1. To implement the Air Carrier Access Act of 1986, the Department of transportation passed this law.

   DOT Part 382

2. These are the two types of animals trained as service animals for individuals with a disability.

   Dogs and Monkeys

3. This is the best way to determine how to assist a customer with a disability.

   Ask

4. Give two examples of Organic Brain Syndrome.

   Senile, dementia, Alzheimer, brain injury, subdural hematoma (blood clot), concussion, hemorrhage. Symptoms, confusion, delirium, short term or long term lose of brain function.

5. Give three examples of non-visible disabilities as defined by the ADA and DOT Part 382.

   Special Sense Organs, Respiratory, Speech Organs, Digestive, Reproductive, Genito-Urinary, Hemic, Lymphatic, Endocrine, Epilepsy, etc.

6. What is the maximum number of medical oxygen bottles allowed on the aircraft as defined by Continental's policy.

   12

7. Give two examples of disabilities in which the customer is ambulatory.

   Blind, deaf, speech, etc.

8. Why is it important to keep a disabled customer's wheelchair in the 1st class closet on a flight from the United States to an international location.

   The wheelchair will not have to clear customs.

9. Who was the President of the United States who signed the Americans with Disabilities Act into law?

   George Bush

10. What is the name of the signed language used by people who are deaf?

    American Sign Language (ASL)

11. Who was the first President elected to office with a visible disability?

    Franklin D. Roosevelt

    Bonus: What disability did FDR have? Polio

12. The movies that Tom Hanks received two Academy awards for his portrayal of a person with a disability.

    Philadelphia and Forrest Gump

13. The actress who won an Oscar for her performance in "Children of a Lesser God"

Marlee Matlin

Bonus: What disability did she have? Hearing Impaired

14. What is the purpose of DOT Part 382?

Ensure non-discrimination for customers with disabilities in air travel

15. What is the estimated cost for wheelchair damages that Continental paid out in 1997?

1 million (Take the closest answer)

16. Give two examples of communicable diseases as defined by the Center for Disease Control, that you may deny boarding to a customer for having.

There are none

17. The medical service the requires advance notification.

Oxygen

18. Give two examples of services Continental provides to customers with hearing impairments.

TDD res phone and open captioning on flights where the safety briefing is completed by video.

19. Continental may refuse transportation to a disabled customer for _____.

Safety

20. What is the maximum liability on an electric wheelchair.

$2500

TRUE/FALSE QUESTIONS

1. The unemployment rate is the same for people with disabilities is the same as those who are non-disabled.

   False The unemployment rate for people with disabilities is 70%.

2. A customer with a disability traveling with a service animal that does not have documented proof of being a service animal, will be checked as baggage.

   False Not all states issue documented proof of service animal training. A verbal assurance from the customer is adequate identification.

3. Dennis Walters is a motivational speaker, that was paralyzed in a golfing accident.

   True Dennis was paralyzed in a golf cart accident 24 years ago, and now makes his living as a speaker / trick-shot golfer.

4. Guillian-Barre Syndrome is known as the "Mysterious Paralysis." Affect more than 8,000 Americans annually.

   False It affects 2,000 - 3,000 Americans annually.

5. Common phrases/expressions used like "See you later", or "Take a walk", are offensive to individuals with a disability that seem to relate to a person's disability.

   False Source, The President's Committee on Employment of People with Disabilities, 1995.

6. At least 60 million Americans will have a psychiatric disability at some time during their lifetime.

   True Source, The President's Committee on Employment of People with Disabilities, 1995.

7. John Kemp, President and CEO of Very Special Arts was a born without lower arms and legs, was a poster-child for Easter Seals.

   True New Mobility magazine, January 1998 issue named John kemp "Person of the Year".

8. At "The Seeing Eye" each dog spends four months in training before being matched with a person.

   True "The Seeing Eye", press release. After completing 4 months of training with a handler the dog is matched up with a person and they together will spend an additional 20-27 days in training.

9. The ADA allows individuals with a disability to sue a business before a discrimination occurs if the allege discrimination is based on a reasonable belief.

   True The ADA: Questions and Answers, Public Accommodations

10. Employment provisions of title 1 of the ADA are not enforced under the same procedures applicable to race, sex, national origin, and religious discrimination under the Civil Rights Act of 1964.

    False The ADA: Questions ans Answers, Employment

11. There are only three states nationwide which have comprehensive, detailed travel guides for persons with a disability.

    True Open World travel brochure, page 11

12. The Independent Living Research Utilization (ILRU) was founded in October of 1990.

False October 1st, 1977, 1996 Disability Media Calendar

13. Parkinson's disease is a chronic degenerative muscle disease.

False It is a chronic nervous disease characterized by a fine slowly-spreading tremor, muscular weakness and rigidity, and an irregular gait. 1994 Disability Media Calendar.

14. 1972 was the first annual Muscular Dystrophy Telethon hosted by Jerry Lewis.

False September 1981, 1994 Disabilities Media Calendar

15. The Metro subway system in Montreal is not accessible to wheelchair users.

True Article from New Mobility, ADA, Non; Access, Oui

16. The National Theatre of the Deaf established in 1967, uses a signature style of both Sign Language and the spoken word.

True Enable magazine, premiere issue

17. In 1995 the Aviation Consumer Protection Division established a new tracking system to monitor air carrier compliance with DOT Part 382.

True See Enable magazine premiere issue page 23

18. All auto manufactures offer a rebate of $750 - $1000 to pay for special equipment.

False Only GM, Ford and Chrysler. Enable magazine premiere issue.

19. The United States will send 45-50 athletes to the 1998 Winter Paralympic Games in Nagano Japan.

True Enable magazine, January 1998

20. 300 pounds is the maximum weight of a customer, that a Continental employee must assist in lifting/transferring.

False

21. Service animals are required to sit in a non-exit window seat.

False

22. All Continental 737-300 & 500 series aircraft have moveable armrest on all rows except First class and emergency exit rows.

True

23. Service animals traveling with a handler/trainer are not allowed in the cabin of the aircraft, unless they meet carry-on pet requirements.

False CO policy, DOT Part 382

24.

GOOD LETTER

12-3-97

Dear Sir or Madam,

I would like to commend one of your employees on duty at Newark Airport.

Ms. Leslie Heard assisted my mother a few days ago. I was late and my mother had no one to meet her at the gate. Leslie Heard took control immediately, since she observed my mother in a wheelchair and confused. She continually reassured my mom that everything was going to be all right and she would not leave mom's side. When I came along, she took us right to baggage and escorted us to our car.

I can't convey to you how much this meant to an elderly person dealing with the overwhelming situation of Newark Airport. The person who trains your employees deserves credit also, I noticed how tuned in to the elderly they all were.

Once again, Leslie Heard, a kind person and an excellent employee.

Sincerely, Catherine Curry

World Class Supervisor
Workshop Flow

Day One

1100 – 1130	Registration	
1130 – 1200	Opening	
	* Video "A World Class Supervisor is . . ."	3 minutes
	* Welcome by Mark Erwin (3/2 – Joe Megna)	15 minutes
	* Logistics – Colleen Picard	12 minutes
1200 – 1300	Lunch (G.Bethune to speak 3/12)	
1310 – 1445	"Thinking and Operating as an International Airline"	
	* Destination Icebreaker – Colleen Picard	20 minutes
	* Alliance Presentation - Tom Barber	30 minutes
	- Purpose and benefits of alliances	
	- Northwest/Continental Alliance, and the 3 phases of implementation	
	* Alliance Q & A – Tom Barber	15 minutes
	* Passport Activity	30 minutes
1445 – 1500	Refreshment Break	
1510 – 1700	Rotation One	
1700 – 1800	Refreshment Hour	
1800 – 2100	Dinner – *"Around the World"*	
	* 5 food stations around the room with food selections and décor from different countries	
	* DJ playing international music selections	

Day Two

0800 – 0830	Continental Breakfast	
0830 – 0920	Opening	
	* Welcome Remarks - G. Brennemen – 3/3 & 4/21 FBL or Hub VP – 3/5, 3/13, & 4/23	15 minutes
	* Logistics – Colleen Picard	15 minutes
	* Latin Bag Relay – Colleen Picard	20 minutes
0930 – 1120	Rotation Two	
1130 – 1230	Lunch (G. Bethune to speak 4/23)	
1240 – 1430	Rotation Three	
1440 – 1630	Rotation Four	
1640 – 1700	Close	
	* End Remarks – FBL/Hub VP's	15 minutes
	* Logistics/Workshop Evaluations	12 minutes
	* Video "Picture a World Class Supervisor"	3 minutes

**** See attached for <u>Rotation Topics</u> Overview**

World Class Supervisor

Brief Synopsis and Overview of Rotation Topics, Activities, and Videos

General Session – *"Thinking and Operating as an International Airline"*

- **Destination Icebreaker** – In 10 minutes supervisors work together at their tables to identify from memory as many international cities by 3 letter code which Continental flies to – not including Alliance partners. Table with the most international city codes correctly identified wins prizes for each supervisor at table.

- **Alliance Presentation and Q & A** – Tom Barber facilitates the group through a 30-minute power point presentation and 15 minute Q & A designed to educate the supervisors on the purpose and benefits of our different alliances. Specific focus will be on the Northwest/Continental Alliance, and explaining the 3 phases of implementation. This will include thru check-in as part of the "Quick Start" plan.

- **Passport Activity** – A highly interactive exercise, designed to encourage international, hub, and domestic supervisors to interact. At check-in each supervisor is given a "passport" and a supply of "passport stamps" from their individual cities. In the passport, a number of Continental destinations, both domestic and international are listed in alpha order. Each city has at least one question, which the supervisors will need the assistance of supervisors in those cities to answer. As the supervisors locate other supervisors from different cities and gather the answers to the questions, they need to get a stamp from the supervisors who assist them with the answer. The supervisors are given 20 minutes to interact, with a 10 minute debrief to identify the individual or individuals with the most correct answers and stamps.

- **Latin Bag Relay (day two)** – An activity designed to reinforce the need to be consistent in the Latin Bag Policies. Supervisors are divided into 10 groups (identified by table seating). Each table will be given a scenario, which outlines a customers need to check in for a Latin flight. Outside the room, are 10 sets of luggage, which corresponds, with each scenario. A bell is heard, and in 10 minutes or less, each table has to work together to identify if the bags meet the CAL requirements, and if not, they will need to "bring them to specifications". The table which completes the task properly and returns to their table first are the winners. A 10 minute debrief is allowed to identify winners, and discuss results.

Rotation Topics

- **Ensuring a Safe Culture at Continental** – Designed to identify strengths and areas of focus. Participants were sent a pre-work assignment to complete a self-audit. During the session statistics will be shared on how we are doing as an airline in the area of safety with OJI's, equipment damage, etc. The participants will discuss their individual audits, formulate a station action plan, and present the plan to the other participants. Bill Plisga and Ron Failing, Ground Safety/Risk Management will facilitate the sessions.

- **Maximizing Your Resources** – A session designed to take a "common sense" approach to creative scheduling and work schedules. In addition, supervisors will learn about managing key steps . . . recruiting, training, work schedules, etc. Finally they will look at techniques and ways of implementing a plan which is essential to being productive and taking the necessary risks to ensure we are financially competitive and operationally sound. Mark LaScola, MFE GM, Kirk Holmes, SFO GM and David Dirickson, Director Airport Services – IAH, will lead the facilitation of the sessions.

- **Serving Customers with Disabilities** – A highly interactive session designed to educate the supervisors on how they can manage meeting our customers with disabilities needs. The sessions will be facilitated by Stacey Toomey, Airport Services, and representatives with disabilities from TIRR

- **Treating each other with dignity and respect** – Part One of this session is a review of the HR tool kit, with both international and domestic coverage. Part Two is "Do Your Part", the 1998 initiative for a harassment free work place. HR facilitators will include Rich Fulmore and Karen Radabaugh, and International HR representatives, Peter Beck, Deborah Edwards, and Allyson Healy.

Videos

"A World Class Supervisor is . . ." – A 3-minute video to open the workshop on day one consisting of several different individuals, from the front-line to all levels of management in Field Services commenting on what they think a "World Class Supervisor" is.

"Picture a World Class Supervisor" – A 3-minute video to close the workshop on day two. It is shots of supervisors in action, taken throughout the system, set to music. Mark Erwin does a voiceover at the end thanking the supervisors for their work in making us a World Class Airline!

Wednesday, August 12, 1998

Lex:

1) For Fred Fay: Dr. donovan recommends he call Boston Medical Center PM&R Department at (617) 638-7358 or their connection, Allen Meyers, PhD., who is in the PM&R Dept. At (617) 638-4510.

2) Jennifer MacMillian needs the stuff on disk.

3) Press release for Desta. Copy of tape for DeValca.

4) Madan. Talked to Councelor's office. If you request the refund of unspent funds, they may refund it. Also wants a letter of support for the long-term training grant.

5) Gene Rogers (512) 929-7776.Finishing up a Switzer fellowship on community based rehab. Do you know of agencies that he can write a grant for or proposal to start a pilot program in Tx? It would be simple and low-cost.

6) Ralph Rouse (214) 767-4058. Meeting he invited you to re Helen Ell?? Is September 24 and 25 (th &Fri) plans to invite key leaders: Steve Gold, Medicaid directors, HCFA, Asst. Secretary for Planning and Evaluation, OCR.

7) Howard Green, Virginia, support letter

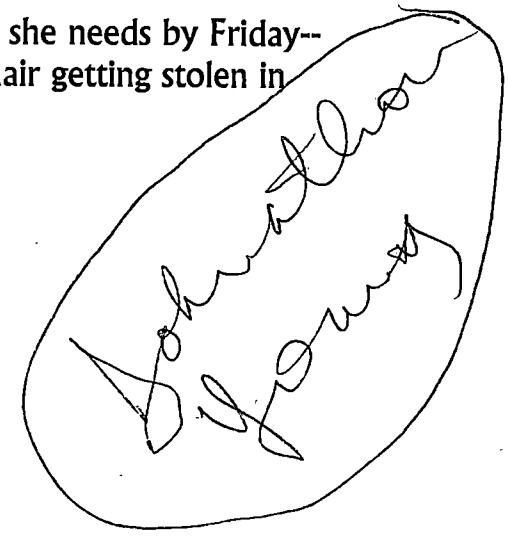
8) Laurie, Oregon, needs letter of support.

9) Call Roland at (937) 237-8360

10) Call Gerben at 3:00 our time. (202) 466-1903

11) Wendy called about Leadership Houston and funding she needs by Friday--can ILRU help her? Ask her about the story of her wheelchair getting stolen in Detroit.

+ Are you going to DC?



- ~~Follow up + Get Rpts for Research Lauriel Daniels~~
- Call Nancy re press release — have me go over
- Clean copy for Death Dut Microwave
- Mailed press releases Wires List + Mail press release
- Phone Bill
- Vet mtg w/ Cathy Nuff

Lap to Sf up Roxy

- NW ga DBTAC calls setup
- 110 mtg — Bill?
- Call Travel agencies
- LA or C Beall

Japan
names
+ Bromley
[illegible]

Paul Big Louis

[illegible]
[illegible] p.00314
[illegible]
[illegible]
[illegible]
Iolani [illegible]

Yan Sushi

call Pamela
do a [illegible]
our [illegible] on
[illegible] care
w/ Lex
[illegible]

1 Drs Case Long
Aug. 3.

What [illegible]
[illegible] Drs Las
Sept 21.
rei our [illegible] on
the glass ceiling
[illegible] AOA [illegible]
B[illegible] w/ Lex.
their names 1st

Funchess, Roxy

From: Frieden, Lex
Sent: Friday, August 14, 1998 10:08 AM
To: Funchess, Roxy
Subject: FW: listserv info

-----Original Message-----
From: June Isaacson Kailes [SMTP:jik@pacbell.net]
Sent: Thursday, August 13, 1998 2:39 PM
To: Frieden, Lex; Dautel Pam; 'jik@pacbell.net'
Subject: listserv info

information

Suggest you sent it out to past managed care meeting participants and do a flyer for the meeting at the end of the month.

You are invited to participate in

The Health, Wellness and Aging with Disability
Mailing List

WHAT THE LISTS FOCUS IS:

This mailing list will alert you to news items, conferences, web sites, and publications that explore disability-related managed care, health, wellness and aging issues. You will receive selected periodic mailings, typically once or twice a month.

SPONSOR

This mailing list is sponsored in part by the Independent Living Research Utilization (ILRU) program at TIRR, Houston, Texas.

WE PROMISE NOT TO YOUR FILL MAILBOX E-MAIL WITH DAILY OR WEEKLY E-MAIL.

Please Note that this mailing list replaces the previous "Aging with Disability" mail list.

HOW TO SUBSCRIBE:

Send a message to majordomo@tripil.com with the following text in the BODY of the message (subject line is ignored)

subscribe hwawd

You do NOT need to include your address or name, the mailing list will figure that out correctly on its own.

TO POST MESSAGES TO THE LIST:

This is a moderated list which means messages are screened before they are posted. If you have information that you would like to have sent out on this mailing list, please e-mail it for consideration to: June Kailes jik@pacbell.net

TO END YOUR SUBSCRIPTION:

Send thus messeage:

unsubscribe hwawd

TO CHANGE YOUR ADDRESS:

If you change E-mail address changes PLEASE unsubscribe your old address and then subscribe using your new address.

ARCHIVES (PRIOR MESSAGES):

You can find prior messages on:
http://www.dimenet.com/hwawd

Selected postings can also be found on:
http://www.jik.com/pwdm1.html
http://www.jik.com/hwawd..html
http://www.jik.com/resource.html

ADDITIONAL ASSISTANCE:

Send e-mail to jik@pacbell.net

--
June Isaacson Kailes 310.821.7080
310.827.0269 FAX
Disability Policy Consultant jik@pacbell.net
June's Web site http://www.jik.com
IL Net http://www.ilru.org
RTC Aging with Disability http://www.usc.edu/go/awd
U.S. Access Board http://www.access-board.gov

Long-time activist Bob Kafka calls for "the next evolution of the independent living movement"

Empowering Service Delivery

by Bob Kafka

Since the start of the independent living movement 20 years ago, we've been debating the role independent living centers should take in delivering services. What is the role of a "true advocate?" we've asked. "Should we become part of the system, or should we stay outside?" These debates have occupied many hours of conference time over the years.

We must get beyond this debate!

Purists have argued that "pure" advocacy would be co-opted by the economic pressures of a service delivery role. Instead of being a strong voice for the interests of a disabled person, they've said, a Center that delivered services (and saw itself as part of the service delivery system) would become more interested in the bottom line, or in keeping a contract with a state agency. These purists have insisted that only by being outside the system can one truly advocate for the things necessary to change the system.

This argument, though, is becoming more and more difficult to sustain. While Nero fiddles, Rome is burning. People with disabilities are demanding more than rights: they are demanding services. Almost two million people with disabilities, young and old, are locked away in nursing homes and other institutions, unable to use the rights promised them by passage of the Americans with Disabilities Act. While the disability community has this intellectual argument, services vs. advocacy, our brothers and sisters lie in bed waiting for real alternatives to institutionalization.

The healthcare system in this country is drastically changing the way acute medical services and long-term support and services are delivered. This change is occurring at a rapid pace. The disability community must be at the forefront of these changes or be relegated to a minor role. People with disabilities, including those of us with long-term care needs, have been fighting to be excluded from the managed care juggernaut based on the belief that the cost of our services, rather than our service needs, will be the incentive that motivates the managed care organization.

But while we fight, pilot programs around the country are already testing how best to serve people with disabilities using managed care concepts, both for acute and long-term care services. Managed-care providers are already talking about "carve-ins" or "carve- outs" of specific disabilities; talking about integrating acute and long-term care needs; debating whether entrance into the managed care system should be voluntary or mandatory.

The economic imperatives that fuel the managed-care train today are too powerful to stop. Even if managed care changes its look, a "managed care" (read: "save money") approach will soon subsume the whole health care delivery

Bob Kafka is an organizer with ADAPT.

The economic imperatives that fuel the managed-care train today are too powerful to stop. Unless we people with disabilities are at the table telling managed care corporations what concepts we want in a delivery system, we will find that we will continue to be at the mercy of providers who understand little about our functional needs and even less about the independent living philosophy.

system. The disability community must deal with this issue directly and not stick its head in the sand and hope it will go away. The question isn't "if managed care..." but what managed care will look like as we move into the 21st century.

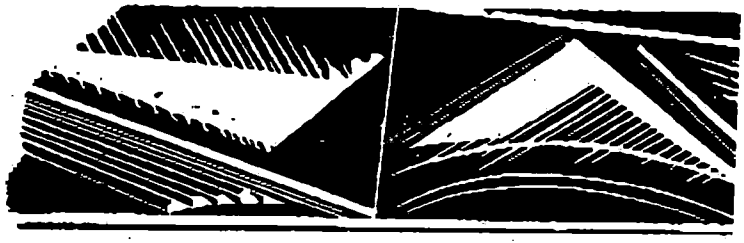
So: what role does the disability community want to play in this managed-care delivery system that's upon us? What role will the disability-rights and independent-living community play in the long-term care/personal attendant service delivery system when people with disabilities start being absorbed into managed care programs around the country?

Unless we people with disabilities are at the table telling managed care corporations what concepts we want in a health care delivery system; unless we ourselves start the process of becoming what I call "empowered service deliverers" ourselves, we will find that we will continue to be at the mercy of health care providers who understand little about our functional support needs, and even less about the independent living philosophy.

"Empowering Service Delivery" is my name for an old concept. Since the beginning of the independent living movement, the challenge has been to put independent living philosophy concepts into the larger systems — and only provide services on an interim basis till the larger system has changed. ESD is an interim step I propose we take till the larger long-term care/personal attendant service system embraces independent living concepts.

This approach to changing the current service delivery system would have independent living centers become service providers — and put the independent living concepts of choice and control into operation through a delivery system: independent living centers as deliverers of long-term care/personal attendant services.

Although there's been a lot said and written about how people with disabilities can individually become more empowered, there's been very little said about how the delivery system itself can become empowering for people with disabilities.



The disability movement has often — and for good reason — cast the delivery system of nursing home, "home health" and ICF-MR providers as the "medical-model" enemy of disabled people. Though this is true, changing that "medical model" from outside has been a slow process. "Empowering Service Delivery" would allow us to expand our strategy to advocate for changes in the larger system from the perspective of a progressive insider.

The disability community needs to take a lesson from other minority groups who have effected change by taking economic control of their neighborhoods. We, people with disabilities need to take economic control of our "neighborhoods," too.

To racial minorities, "taking control of the neighborhood" meant taking economic control of the system that delivered goods and services to their own communities; by doing this, they gained control over what happened in their communities, and also brought their own cultural perspective to the community. Since people with disabilities all don't live in one neighborhood (unless you consider nursing home and other institutions "neighborhoods"), our "taking control" must take another form.

The analogy works like this: people with disabilities should take over the pieces of the health care delivery system that for years have controlled our lives. Independent living centers should become deliverers of personal attendant services.

If a person with a disability calls up an independent living center today and wants to get out of an institution, what can the majority of them offer? Classes? Information and referral? Peer counseling?

To begin the process of becoming independent, that person first needs to be able to get out of the institution. Being able to get someone out of an institution — or keep

Continued

someone out -- is truly what the independent living movement is about.

If we don't provide ESD ourselves, consider what "providers" we have to battle: The American Health Care Association— the nursing home providers. The National Association of Home Care -- the "home health" service providers. Other professionally-driven health care providers: Occupational therapists. Physical therapists. Social workers. Psychologists. And on and on.

Disabled people are always on the outside — we're the "crop" for a lucrative, profit-driven health care system that harvests billions of dollars from us (or our Medicare, Medicaid or insurance companies) — based on their definitions of our needs. ESD allows us to directly confront the paternalism in the existing system and make changes from the inside. It also puts some of that money back into our organizations, money which can then be used for advocacy efforts such as enforcement of the ADA, affordable and accessible housing and community organizing activities.

The traditional disability rights movement's response has been simply to shun the "medical model": make believe it doesn't exist and attempt to totally bypass the delivery system. An agency model, even one that might be progressive, has been shunned. The model promoted was one where individuals would hire their own attendants and, in essence, run their own "service delivery system" by being in charge of one — or more — attendants, managing their funds, reimbursement and all the rest.

The Topeka Independent Living Center, the Atlantis Community in Denver and Liberty Resources in Philadelphia have been providing cost-effective personal attendant services for many years -- and also have a reputation of doing aggressive advocacy work — showing that services and advocacy can go hand in hand.

This traditional independent-living movement approach to how personal attendant services should be delivered may work for some individuals who have the desire and skills to run things on their own. But for the vast numbers of people who have disabilities, it's just not working. Sticking to this one approach to personal attendant services delivery will not meet the diverse needs and skill levels of the disability community. Independent living centers need to develop a complete service delivery system for personal attendant services.

Let me give you an example of why we need a delivery system in place: The U.S. delivered tons of food to the docks in Somalia to help feed starving people — but at that point it wasn't real "food" to the people of Somalia. Until it got to the people, it might as well have been cardboard. There had to be trucks found to move the food into the villages where people lived. Somebody had to load the trucks. Somebody had to drive them. Gasoline had to be found to fuel the trucks. Somebody had to decide what food went to which villages. Once there, somebody had to unload the trucks. All of this is a "delivery system." Only after a "delivery system" was working did the food reach the people. There had to be a delivery system.

It's no different with delivering attendant services.

Right now, the vast majority of attendant services are provided by home "health" agencies. The disability community doesn't like that; we're not in control, and we view the agencies as coming out of the evil "medical model." The bottom line, though, is that without an alterna-

FREEDOM WATCH

HCFA, DOJ and the ADA

"Freedom is now within our reach" say ADAPT activists. Both the Department of Justice and the Health Care Financing Administration (HCFA) have issued letters insisting states' Medicaid programs comply with the Americans with Disabilities Act. Recent ADA lawsuits have showed this means funds must be used to let people live in their homes rather than nursing homes.

A July 6 letter from DOJ Civil Rights Division Chief John Wodatch to ADAPT organizers Mike Auberger and Bob Kafka says a "fundamental requirement" of the ADA is that states "administer services...in the most integrated setting...." On Aug. 3, HCFA Director Sally K. Richardson issued a letter to state Medicaid directors reminding them of HCFA's "commitment to and responsibility for ensuring compliance with" the ADA, adding that "if necessary, HCFA will refer matters to the... Department of Justice for legal action." The letter's online at http://hcfa.gov/medicaid/smd8398.htm

Readers wanting specifics on using the documents' strong words to get folks out of nursing homes can call the Topeka Center for Independent Living for how-to

tive delivery system in place, people with disabilities are at the mercy of the home health industry. In some states, a few disabled people manage their own attendants and avoid this; they participate in tiny programs that use vouchers, "fiscal agents" or "direct pay" programs.

But although these can be effective ways to have control over the services, it's been shown they don't work for the vast numbers of us who need some sort of a delivery system to deliver attendant services.

Many people with disabilities use the traditional "medical-model" delivery systems already in place because there are no alternatives available. An ESD alternative would give many people with disabilities the alternative they have been looking for —a program run by and for people with disabilities instead of "business as usual" the home-health agency way.

Delivering personal attendant services in an empowering way means interjecting independent living principles into the delivery system. Under such a system, disabled people would be able to select, manage and dismiss their own attendants. If independent living principles were at the basis of the delivery system, the "health" services that often go along with delivery of attendant services wouldn't have to be delivered by a doctor or nurse as has traditionally been done; they could be delegated or "assigned" by a nurse or doctor to a qualified but unlicensed person. Services would be designed to enhance the person's ability to function in the community, rather than to "fix" or "cure" the person.

If the independent living movement were to take over the delivery of personal attendant services, we wouldn't have to be "just like the current system," as people fear. We'd bring the disability community's unique perspective of choice and control to the hands-on delivery of services.

Through the concept of "empowering service delivery," the disability-rights and independent-living communities could change the way attendant services are deliverod. We wouldn't be traditional "home health agencies"; we could change our names and call ourselves Home and Community-based Support Service Agencies — or HCSSAs. Our philosophy would shape the service delivery system.

Disabled people are always on the outside — the "crop" for a lucrative, profit-driven health care system that harvests billions of dollars from us.

HCSSAs would be consumer-driven. They'd be as non-medical as possible. They'd work with people with disabilities instead of against them. People who wanted total control over their attendants would be able to use the HCSSA as a "flow-through" for the money they paid their attendant so the HCSSA would be able to provide a consistent system for accountability to the funding source. Our concepts of choice and control would permeate the traditional system. Our presence could assist advocates working to change the larger home health industry.

Yes, it's true that HCSSAs could succumb to the same pressures that home health agencies say they're up against. Sometimes the consumer of services might get angry at us, too. The truth is that it's difficult to deliver any service competently all the time — including personal attendant service. Yes, we'd make mistakes. But having the agency based on the independent living/consumer-driven philosophy would be some protection against our becoming co-opted by economic and political pressures in the traditional sense.

Though HCSSAs may not be the total answer to changing our traditional delivery system, if the independent living movement moved in this direction many people who are in nursing homes and other institu-

Continued

Somalia

Let me give you an example of why we need a delivery system in place: The U.S. delivered tons of food to the docks in Somalia to help feed starving people — but at that point it wasn't real "food" to the people of Somalia. Until it got to the people, it might as well have been cardboard. There had to be trucks found to move the food into the villages where people lived. Somebody had to load the trucks. Somebody had to drive them. Gasoline had to be found to fuel the trucks. Somebody had to decide what food went to which villages. Once there, somebody had to unload the trucks. All of this is a "delivery system." Only after a "delivery system" was working did the food reach the people. There had to be a delivery system. It's no different with delivering attendant services.

tions would finally be able to live in the community. This is real independent living.

As "empowered service deliverers," HCSSAs could be there to provide community-based personal attendant services when a person is coming out of a hospital or rehabilitation facility as well as the other services provided by the independent living enter.

Managed care entities are grappling today with how to move people from "acute" environments — hospitals, rehab facilities — into the community. Independent living centers have the answer to this problem: they can — as they've traditionally been supposed to do — not only provide the personal attendant services, but also locate accessible and affordable housing, information on assistive technology and offer a range of other services which most of our centers provide today anyway.

An "empowered service deliverer," armed with the ability to deliver actual services, would provide the individual the ability to truly become independent and a way to become active in the community.

Delivering services in this way can be efficient and cost-effective. Filtering out the over-medicalization of services has been a goal of the independent living movement for years. Independent living centers as "empowering service deliverers" can prove to managed care organizations, through their effective use of a non-medical and more efficient model, that the medical model is costly and doesn't work nearly as well as the independent living model.

The Topeka Independent Living Center, the Atlantis Community in Denver and Liberty Resources in Philadelphia have been providing cost-effective personal attendant services for many years. These centers show that ESD can work. These centers also have a reputation of doing aggressive advocacy work. They show that services and advocacy can go hand in hand.

Unnecessary case management, and too many professionals in our lives, are also areas where cost savings wouldn't be a dirty word. Many of our Medicaid waivers are based on the idea that we are "broken" and that professional services can "fix" us. With ESD, independent living principles, rather than "medical model" concepts, would form the basis for evaluating whether a particular service would be of "benefit" to a client. Rather than seeing a client as someone to be "fixed," it would see a client as someone who needed services to function in the community. The measure of a service's success would not be a medical professional's evaluation; the measure of success would be in how well the clients are able to go about their lives in the community.

Infiltrating the health care delivery system from within, as well as pushing for change from the outside (as we've traditionally advocated) are not strategies that need be mutually exclusive. The independent living philosophy that spawned the independent living centers of today needs to progress to the next stage nd truly "empower" the delivery system itself. This is the next evolution of the independent living movement. ■

House Guest
(For Nonnie)

This morning I thought of you in that instant
I bent to load the dishes and arose,
holding breath and counter top in crippling
embrace. Greedy for writing time, I logged
Sunday's fire with the mastodon of the pile
who bit me then, leaving the long tooth
to pierce again at 3:00 a.m.
Thirty years ago I watched my cousin
carry you down the steep river path
carved in the bluff for surefooted fishermen
carrying only rods and creels.
Through medical school and family practice,
family deaths and his escape, you carried
him, three children, your parents, childlike
in divorce, dropping them only at journey's
end accompanied always by the silent
one you didn't choose, nor introduce, nor
ever lose. For three days I've favored my
companion, hoping he'll grow bored with me
and have no wish to linger like an old
fish forgotten in the fridge, too rank
to touch or to remove. Too long I've watched
him, love struck, your incubus, remain
to watch Troy burn again in your pain.

— *Frances Douming Hunter*