



Connections for Information and Resources on Community Living (CIRCL)

February, 2000

Volume 3, Number 2

Ingrid's Story

As told to Sherry Beamer



Over ten years ago Carolyn Colwell described Ingrid in "Newsday," a newspaper magazine:

"Ingrid can't walk and she can't talk. And when she gets excited, a river of saliva runs from her mouth like water gurgling over rocks. She spends her days in a geriatric ward of a California State Hospital. There her closest friend is an 84 year-old Alzheimer's patient named Katherine. Ingrid quietly endures. She sits by a table and points to letters on an alphabet board to spell out a message to a volunteer aide. On the back of the cardboard there are phrases ready to telegraph her thoughts and wants – such as "Let's Play Trivial Pursuit," "I Love You," and "Take Me For A Walk." At her side are other survival tools: a towel to dam the river, a Bruce Springsteen tape and a Danielle Steel paperback.

Ingrid is a prisoner who has committed no crime. She is trapped in a locked ward, trapped in her wheelchair and trapped in her body by a genetic illness called Wilson's Disease, one of the rarest maladies known. This means that her liver can't maintain the balance between the copper that lurks in common foods as broccoli, chocolate and mushrooms and the trace amount of copper that her body needs. The result is gradual copper poisoning."

The first thing Ingrid says anyone needs to know about Wilson's Disease is that it "is not a mental disease, but a physical one." When Ingrid was 18, the experience of the disease started to unravel. After many difficult years of misdiagnoses and difficult living experiences, Ingrid is where she wants to be.

Ingrid has been living in a condominium apartment in Ventura, California, since August of 1997. She lives a very busy life! Ingrid participated in this interview with her new computer, and also speaks while on the run through her Dynavox communication device. She receives supported living services 24-hours a day from

continued on page 3

If you have questions . . .

Becky Donofrio

135 E. Live Oak, #104
Arcadia, CA 91006
(626) 447-5477 fax 447-5855
sltea@aol.com

Claudia Bolton

P.O. Box 1084
El Dorado, CA 95623-1084
(530) 521-1933 fax 621-1933

Vickie Vining

5835 St. Clair Avenue
Valley Village, CA 91607
(52-7484 fax 508-1265
vvining@earthlink.net

IN CHARLIE'S SHOES

By Donna Bettencourt
Sacramento Vocational Services



These shoes I am wearing were hardly worn when I received them. They belonged to a man who had little use for shoes. On more than one occasion, backseat passengers found them sailing past their window as he threw them out the front window. He shuffled when he walked; the soles were worn evenly with little wear to the heels or the toe. He always had the best shoes – Nike, New Balance - tennis shoes, hiking boots, walking shoes. Charlie's dad always saw that he had the best shoes.

When Charlie died last year, all his gently worn shoes ended up in a large cardboard box on the front porch of his house in his east Sacramento neighborhood. I came over to welcome Eddie, the new roommate of Charlie's bereft former roommate, to the new home. Charlie's absence had created a rare opportunity for a man who had spent his entire lifetime in board and care facilities and before that state hospitals. I welcomed him and noted the cardboard box labeled "Please pick up" on the front porch.

I mentioned the box of shoes to Eddie and to others present that early afternoon. I picked out two pairs from the box. Would they fit Eddie? No. How about Pete? then surely they will fit Mike. On his staff salary, he could use some good shoes. No, too small. They seemed destined for the thrift store, until Mike said, "How about you?!!" I tried both pairs on and they fit perfectly. I had known and supported Charlie in his struggle to live a good life for over 9 years. I had been by his bedside on two occasions in the emergency room and on another at his bedside in the hospital after major surgery. I still laugh when I remember Charlie laying on the gurney in the emergency room after a rainy February day caused a driver to hit the car he had been driving in. His eyes were wide and he was mute, as he always was, except when he seized. The ER nurse commented as she breezed by, "Don't worry; I'm sure that he'll be able to speak with you as soon as the neck brace is off." I wished he could have.

The summer after Charlie died, I travelled north to the Anacortes Islands, shod in Charlie's shoes. "You are wearing a dead man's shoes?" my mother asked. At first, there was a certain morbidity to wearing his shoes, as I laced them up. After a while, that feeling left as I took Charlie on my travels. I hiked up to the top of Mt. Independence in Moran State Park in Charlie's Nike hiking boots. I stood on the deck of a sail boat and watched orcas whales leap in the waters off Canada. I danced with my three year old son in an old Orcas Island orchard in Chuck's sneakers. When I returned to Sacramento, I wrote my testimony for the recent legislative hearings on SB1038 with Charlie's tennis shoes tucked under my desk at work. Charlie never was able to see the whales, or hike to that high mountain, and his testimony to the legislature was never heard. And he never danced with his son.

I wore Charlie's shoes in places that he never could; his shoes took me to places that I never could have gone. I literally walked in Charlie's shoes and continue to now. We, as professionals and family members, should remember that we all only attempt to walk in shoes that are not our own.

Thank you, Charlie. For the shoes and for the opportunity to walk in them. I remember you every time I lace them as a Catholic remembers his faith when he fingers his beads. I remember you and the trust you had in me.

Ingrid's Story, continued

Progressive Connections (PC). She says the biggest difference in her living arrangement is “obviously having a wonderful place to live with a pool and jacuzzi, that is close to Ventura College. I got to actually go out and pick out all my furniture. I didn’t have any credit, so the PC staff went with me to the furniture store, and I got the credit and the furniture. The PC staff picked out the place for me as the owner of the facility where I previously resided for seven years gave me a 30-day notice. She didn’t do it to be spiteful, but she did it to light a fire under me, so to speak. She was the first person who actually saw me as able to live in the community. I was referred to a great case manager at Tri-Counties Regional Center.” Ingrid has been living with a young woman named Gerri for eight months. She has had four roommates in the apartment over the last 2 years. Ingrid eventually hopes that both she and Gerri will have their own places someday.

Ingrid works through the Integrated Work Program at Arc-Ventura County three days a week. She works in the Arc office, doing whatever needs to be done, such as typing, copying and collating time cards. She also attends computer classes at Ventura College two afternoons a week.

Ingrid is one of the newest members of the Tri-Counties Regional Center Board of Directors, and is also a member of their Consumer Leadership Council. She freelances as a speaker on disability issues, recently presenting at a disability awareness session for local regional center vendored bus drivers and local consumer conferences. She has also presented at the California People First and Supported Living conferences on her supported living arrangement.

Ingrid also writes poetry, and won a third place ribbon at this year’s Ventura County Fair in the class of inspirational poetry. Her latest poem is dedicated to the memory of JFK, Jr. When asked which of her poems she would like to have printed in this newsletter, she remarked “it doesn’t make a difference to me as long as my poetry makes a difference in just one person’s life.”

Ingrid feels that her current success is based on her “wonderful ‘circle of support.’ Her house manager Kathy is particularly supportive with her “undying faith in me and my abilities to make living on my own in the community really work. I thank God for blessing me with an innovative program.”

What are Ingrid’s hopes for the future? She’d “like to share her own home with a significant other and continue to pursue a vocation of speaking as much as possible – because the actress in me is still leftover from high school.” In closing, Ingrid stated: “I am by no means an angel. I still have got a lot of work to do on myself, such as fully accepting my disability and working on my character. I still enjoy doing much of the same things I did pre-Wilson’s Disease, such as riding bikes, going to concerts and shopping!”

“Success”

*So many of my days
Have been wasted
On old has-been ways,
Now it’s time for a turnaround,
Time to let the good come out.*

*God only knows what’s in store,
Who will I learn from
And who I will teach,
No, I’m not sure exactly what I’ll
succeed
But,
Yes I will succeed,*

*For every smile that I can give,
Or every ray of light
That I can help you to see,
That will be all the reward I need
To just give a hand,
& if you only hold on to a finger
Of all the hope I’ve gotten from above,
Then you, my friend can & will succeed,
For every day you awaken
With hope in your heart,
You have already succeeded.*

© Ingrid Alejandra, December 14, ‘98



March 20-21, 2000



CIRCL Supported Living Gathering in Santa Cruz

Join us to learn, meet old and new friends, get recharged, share dilemmas, problem solve, celebrate what works, hang out or hang ten! The deadline for registration is March 10th. A registration fee of \$125 helps cover the cost of the conference room, breakfast, lunch and coffee/refreshments both days. For a registration form and more information, please call or fax:

Voice (626) 447-5477

Fax (626) 447-5855

For hotel information and registration, call (831) 426-4330.

West Coast Santa Cruz Hotel

(as opposed to the East Coast Santa Cruz Hotel)

175 W. Cliff Drive

Santa Cruz. CA 95060

CIRCL

135 E. Live Oak, #104

Arcadia, CA 91006

CIRCL's mission is to
create opportunities for
building and sharing
individual, organizational
and community strengths
in supported living.

Publisher's Note: CIRCL is currently funded by a grant from the Department of Developmental Services. Newsletter staff include Sherry Beamer and Bill Allen **We need your help in building this newsletter. Please send us any articles, stories, and experiences that you would like to share with others to the address above.**

Has your address changed? If so, please correct the address label above and send it to us.



Community Support Facilitator Interview Questions

Introduction:

Describe the program and the job. Describe the flexible working hours, driving and on-call service. If they can work flexible hours, have a reliable car, proof of car insurance and are willing to be on-call and are still interested continue.

Experience/Knowledge/Skills/Training:

1. Ask about career interests; and why they are applying for the job. Ask about their time commitment to the job.
2. What experience, skills, and knowledge do you have that would make you the right person for the job?

Personal Attributes for the Job:

3. What are three personal strengths you would bring to the job?
4. What are three personal weaknesses you are working on?
5. What are your hobbies and interests outside of work?
6. Are you an active community member? Describe. Do you belong to any community clubs, groups or associations?

Philosophy, Values:

7. How would you describe a person with mental retardation to your friends ?
8. What personal characteristics and skills do you think someone needs to have to live in their own home and receive our support? Do people with mental retardation or physical disabilities need preparation or training before they can be a part of the community?
9. What if a young woman you were working with told you she met a new "friend" and he was coming over that evening? What would you do and say? Are you comfortable talking about and teaching birth control and AIDS prevention?
10. What if you had just helped someone move into their own apartment and their apartment manager called you in the middle of the night and complained that the person was playing their stereo too loud? What would you say to the apartment manager?
11. How would you feel if someone you worked with ran out of money two weeks before they would be getting another check because they spent their money on model airplanes and a trip to Marine World? If they didn't have any food what would you do? Would you feel responsible? Would you lend them any money? What if they needed money to get to work?

Ability to do the Job:

12. Have you ever taught anyone to do anything? Please describe. How would you teach someone to make a grocery list if they could not read and write?
13. How would you help someone to budget their money if they didn't have the ability to distinguish the values between coins and between bills?
14. Have you ever hired anyone or helped anyone hire? Have you ever supervised anyone? If someone you worked with needed your help to hire and supervise their personal attendant, how would you help them? (Ask them to describe the recruitment, interviewing, screening, and supervision process.) (This could be a written assignment at the end of the interview.)
15. Have you ever been responsible for facilitating meetings, work groups or committees? Describe your experience. Do you like to facilitate meetings?
16. Have you ever had a position that required that you write reports, letters or complete paper work? Please describe your experience. How did you keep track of deadlines? How do you feel about having to do paper work?
17. Do you have experience with local community agencies that support people? (like IHSS, Welfare, SSA, Housing)
18. How would you find out about local community services and resources?
19. How would you help someone meet their neighbors?
20. How would you help someone meet people in their community and develop friendships?
21. How are you at juggling several projects and responsibilities at the same time? How do you handle deadlines, competing priorities, and stress? Can you give examples?
22. Do you like to work as part of a team or independently? What experience do you have working independently?
23. What kind of training and support would you need in your first month of this job?
24. How would you feel about providing personal assistance services to people with physical disabilities? How do you feel about helping someone with toileting or bathing? Is there any part of providing personal care that you are uncomfortable with?

In Closing:

Do you have any questions for us?



Special Insert

Supports for Staff Recruitment and Training

Our conversations with many of you in person and on the listserv often are about staff recruitment and training for Supported Living supports. Below are some resources on those topics. Please continue to request and share your favorite resources on the listserv at CIRCL@listbot.com.

Positive Behavioral Supports

There is a continuing shift in thinking about services for people with disabilities who are considered to present “behavioral challenges.” We are learning that we are more successful at assisting people to live the lives they want to live by knowing their hopes, strengths, desires and specifically diagnosing any physical or mental health obstacles the person is facing, instead of thinking about people as a collection of inappropriate behaviors to be controlled.

Volume 2 of the California Department of Developmental Services “Wellness Digest” is devoted to “Behavioral Challenges.” It is an excellent resource of best practices, including the stories of three people with developmental disabilities. Two of the people highlighted are receiving Supported Living Services. Copies of the Digest can be requested from: Wellness Digest • Sue Boucher, Editor • Department of Developmental Services • 1600 9th Street, Room 330 • Sacramento, CA 95814 • E-mail: sboucher@dds.ca.gov

Staff Recruitment

Many of you have been asking for information on recruiting and interviewing staff to fit the individualized needs and preferences of the people served. Aside from the ongoing conversations on the listserv, enclosed in this Special Insert are some staff interview questions that we have found helpful in selecting excellent staff.

Resources

The following are some resources from the CIRCL network for behavioral assistance and staff recruitment:

The Emlyn Group, Essential Human Resources Services

P.O. Box 28815, San Diego, CA 92198 (858) 689-1155

Serves a number of Supportive Living agencies. Features Users Group telephone consulting services. Provides comprehensive services: Human Resource Department set-up or outsourcing, employee handbook and policy/procedures manuals, management development workshops, regulation compliance (FLSA, IWC, ADA), job position descriptions, custom performance appraisal plans, recruitment assistance, executive search, compliance audits, employer of record services, employee relations consulting.

Telemedicine Assessment and Consultation Team (TACT).

Redwood Coast Regional Center • 808 E. Street • Eureka, CA 95501 • (707) 445-0893

TACT provides “whole person assessment and treatment” for people with multiple or complex needs by a group of specialists who come together to assess the whole person, not the presenting issues. The services are offered at telemedicine sites in San Francisco, Ukiah and Eureka, CA. This allows individuals and their families to receive specialized health services via videoconference equipment within 1 – 2 hours from their home. In addition to staff and vendors of Redwood Coast Regional Center, the telemedicine teams include: neurologist, psychiatrist, pharmacologist, developmental pediatrician, dentist, dental hygienist, nurse practitioner, nurse, two behavior specialists. The specialists were recruited and trained by Dr. Ruth Ryan and Barbara Ludwig from The Community Circle in Denver, Colorado.

LaShawn Wells

(925) 673-1760 • E-mail:LBW41@aol.com

Offers staff training on how to respond to assaultive behavior through a “supported living person centered approach.” La Shawn was a P.A.R.T Certified Trainer and has 12 years field experience in social services.