



Colorado Post-Polio Connections

VOLUME 24 NUMBER 2

SPRING 2009

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**A special thanks to Oran
V. Siler Co. and to Easter
Seals Colorado for
printing and distributing
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Paradigm Shift

*By Karen O'Brien, DNP, RN**

When I die, there will be a mound of wheels, metal, plastic and sighs of relief from people that have taken care of me. Picture this: one full leg brace, two half leg braces, 3 pairs of custom shoes, 3 canes, 2 walking sticks, one custom manual wheel chair, two electric scooters, 3 walkers, 2 bath chairs, hand rails in the shower/tub, 2 toilet booster seats, and surrounded by friends and family that assist me literally every step of the way. You could say I have taken advantage of living in the 21st century with all the assistive devices and embracing the opportunity to remain mobile and independent as long as possible. Is it easy? No. Is it worth it? Yes, but there is always a tradeoff.

In the winter 2009 issue of *Colorado Post-Polio Connections* "Informed Consumer Information-Bracing," Margaret Hinman wrote, "The return to bracing because of returning weakness and the effects of aging can result in grief for the loss of former mobility." As a polio survivor of over 55 years living with the effects of paralysis and with determination to live a full life, I have been fortunate to have had many years of increased ability as a result of childhood surgeries and physical therapy. The return of significant weakness and loss of ability has been both a physical and psychological challenge. I have consciously decided to embrace this challenge by tapping into assistive devices such as durable medical equipment (DME), altering my lifestyle, and asking for help when needed. I have assistive equipment in my workplace and in my residences in Arizona and Colorado.

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In My Opinion . . .

I was a patient at Shodair Children's Hospital in Helena, Montana for four months after having had polio. While I was there, I was unhappy with the hospital personnel because they would not let me use a wheel chair to get around. I saw so many of the other children having fun using chairs, racing each other down the long halls, balancing on the two back wheels of their chairs and doing wheelies. More importantly, they were able to get around easily on their own and were able to sit up.

Because I had some weakness on the right side of my back, the doctor and physical therapists would not let me sit up until my back got stronger, fearing, as I learned later, scoliosis and other back deformities. My mode of transportation before I got my KAFO (knee, ankle, foot orthotic) leg brace and forearm crutches was to pull myself along on a gurney, lying on my stomach and using forearm crutches to pull me forward. That way, I was able to be with the other children, get from the second floor hospital rooms and wards, down the elevator, to therapy in the basement and to move around the hospital at will during the day. However, I always envied those kids in wheel chairs.

Today, the least of my desires is to have to use a wheel chair. I still do quite well with a KAFO brace and forearm crutches and I plan my trips out of the house based on what the weather is so I do not risk falling on slick surfaces. I do take advantage of the wheel chair services offered at airports so I can conserve my energy when travelling. Although I can still call upon it when needed, the "I can do it by myself" attitude that I used to have has been supplanted by some sense of preservation. In a word, I want to use my energy having fun, not for getting from one end of an airport to the other.

In the greater picture, when we are ready, wheel chairs, scooters, as well as retrofitted mobility vans are the means for us to get around. They keep us safe and from falling. They conserving our energy, and are tools for continued independence, even if that independence takes a different form. Ultimately it means some life style changes and, for some of us, new adaptability. But as polio survivors, we have had to be adaptable all of our lives. And we can, perhaps, look at that adaptability as a gift that we have been given.

In this issue of the Connections, Karen O'Brien shares her thoughts about embracing all of her wheeled "friends," and Dan Gossert enlightens us, based on his experience, on the task of getting a van.

Jim Oxley shares a story of a husband and wife, JoAnne and Vic Beebe, who have had to be wheel chair dependent almost from the onset of having had polio and who live in a custom built home that accommodates them and their chairs. Also, be sure to check out "And By the Way . . ." to see what other polio survivors have to say about the best advice they have been given regarding polio and Post-Polio Syndrome.

Margaret Hinman, editor

Paradigm Shift

(Continued from page 1)

I have been a nurse for over 35 years and the Colorado Director of Public Health Nursing. My physical decline became apparent over 15 years ago with increased leg pain and decreased ability to walk distances resulting in the need for walking assistance.

During this time, I was offered the opportunity to represent America as a nurse. The People to People Ambassador Program, founded by Dwight D. Eisenhower, provided an opportunity to travel with a group of nurses to Mainland China. We were scheduled to visit both modern and traditional Chinese hospitals, meeting with nurses and physicians. I did the unthinkable, I traveled in a wheelchair. My unspoken message to the Chinese people was that the physically challenged in America have opportunities to contribute meaningfully in our society. In order to take on this kind of physical challenge, I needed mobility assistance and the answer was a wheelchair.

My initial response to a wheelchair was resentment as my body image at that time was one of independence. The wheel chair became a paradigm shift offering freedom from restraint. By accepting the wheelchair into my life, I gained the strength and independence to take on more physically challenging goals and it literally opened up a world of opportunity.

As a polio survivor, I know that the physical limitations will only increase as I age. This is only one part of who I am and one that I can manage through adaptation.

The remaining years can be rich in opportunity by accepting our physical challenges and using the many resources we have in this country. There are resources through Easter Seals and Colorado Post-Polio Advisory Council (see below), among others, to provide financial assistance for DME and other services.

When I die, I have requested an open casket, feet only. I want to be wearing a pair of spiked navy blue and white spectator pumps as my days of needing assistance will be over. I will be dancing and singing with eternal gratitude for this time on earth.

**Karen currently is employed part time at the Colorado Center for Nursing Excellence working under a federal grant that provides leadership training for nurses. She lives the message, "undeserved suffering; unearned Grace."*

News of Note--

The Post-Polio Durable Medical Assistance Fund--Polio survivors in Colorado who qualify can get some help paying for their co-pays for durable medical devices, including braces, crutches, wheel chairs, through a grant of up to \$500.00 by contacting Nancy Hanson at Easter Seals Colorado, phone 303-233-1666, ext. 237, nhanson@eastersealscolorado.org and requesting an application form. These funds are available through the Colorado Post-Polio Advisory Council and are funded through donations.

Persons wishing to donate to this fund can make checks payable to Easter Seals Colorado and designate the funds go to the Post-Polio DME Assistance Fund.

Got Wheels?

By Dan Gossert

Today there are a number of options in vehicles that accommodate the needs of those of us who can't drive a regular vehicle. Devices range from lifts to get a wheelchair (chair) into a vehicle to seats that move to accommodate transfer from a chair into a car or transfer from a chair into a seat when the chair is in the car. And of course, several kinds of driver hand controls are available. The major manufacturers of this type of equipment are: Braun, Bruno, Pride and VMI. When considering a manufacturer it is good to ask about durability; if you know someone with a particular type of equipment ask about their experience with it.

Naturally, all of these devices come with a price. For instance, driver hand controls start at \$1,300.

Lifts

There are lifts that mount at the rear of the car and are exposed to the weather. Bruno makes a model that is somewhat similar to the racks you see for bikes. This type is for folding manual chairs. Heavier duty models will hold scooters and power chairs. Another type has an arm that swings out of the back of an SUV or Minivan. A harness is attached to the chair and hooked to a cable that lifts the chair or scooter and swivels the chair into the back of the chair. The current Bruno model is powered and operates with a remote. One has to be ambulatory in order to use this model and it is best for someone more able to use this equipment.

Another device is a platform that backs out of an SUV or Minivan. VMI and Pride make models of these. The device backs out and drops down in order that a chair can be driven onto the platform and the chair has to be strapped down. The lift is operated with a remote.

I used a VMI lift like this for almost 4 years because I could walk to the back to get in the chair and vice versa. I used bungee cords to secure the chair. Problems for me were days that were very windy or days with ice and snow. And walking on loose gravel is another problem. I paid \$3,000 for this lift and I'm sure they are more now.

Enter vans:

These are usually Minivans that have been adapted for a ramp that comes out the right side via the back sliding door. Considerable modifications have to be made to lower the floor and accommodate the ramp. Basically they all work the same; some have a ramp that folds up next to the side door and some have a ramp that slides out from under the floor. Most have an option that allows them to "kneel." The right side of the car will lower or kneel about 3 inches and is designed so that those in manual chairs can more easily enter. Of course with a power chair you don't need this.

Braun and VMI do these conversions. The price of a new Dodge Caravan conversion from Braun starts in the low \$30,000's. That is the basic conversion and does not include power seats that are about \$2,500.00. Braun also converts Buick and Toyota mini vans. VMI converts Honda Odyssey, Chrysler and Dodge

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Got Wheels?

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Caravan mini vans. The Honda's are pricey going for at least \$50,000 and up to \$60,000. VMI also converts full size Ford vans. These have a ramp that extends out and drops down so that the platform is level with the ground. I don't know what the prices are.

Seating:

If you transfer out of your chair, there are power seats that travel back from the driver controls and swivels to the right for transfer. This is the kind of power seat that I use. There are passenger seats that swivel and drop somewhat from the passenger door, and these are for those who can't enter a seat normally. For those who can't transfer to a power seat, the whole driver seat can be removed so that your chair can be placed in the driver position. The chair has to be locked in position, and there are locks that are manual. EZ Lock makes power-docking system that "locks" the chair into position. There is a mounted control panel with buttons for the locking/unlocking function.

Hand controls:

A popular brand of hand controls is the Monarch. It can be mounted on either the right or left side of the steering wheel. It consists of a bar just under the steering wheel, and the hand bar is just outside the perimeter of the steering wheel. You pull the bar down to accelerate, and you push the bar toward the floor to brake.

Menox makes a hand control that can be installed either to the right or left side. It

is mounted on the floor and has a knob grip like the floor mounted gearshift. I'm sure these are more expensive than the Monarch. Menox also makes pedal adapters so that you can have the accelerator on the left side. They make pedal extenders as well.

Dealers along the Front Range of Colorado:

Adaptive Automobility, 333 E. 76th Ave.
Denver CO - 80229, 800-748-3695.
www.adaptiveauto.com.

Also in Colorado Springs at 6285 Corporate Drive, 877-590-8267

Freewheel Vans, 4901 Ward Road, Wheat Ridge CO - 80033, 303-467-9981
www.freewheelvans.com

Both of these dealers are members of National Mobility Equipment Dealers Association

Rental vans:

Wheelchair Getaways is a national organization that rents accessible mini vans. The web site is wheelchairgetaways.com. The phone is 800-642-2042. I have rented vans in Denver, Phoenix and Oakland and have had good service every time.

My thanks to Mary at Adaptive Automobility for giving me information and brochures.

Being an Informed Consumer When Buying Wheels

By Margaret Hinman

Purchasing wheel chairs, scooters, vans, lifts and other wheeled mobility devices means a significant outlay of money and time, so it makes sense to do the work and the research needed before getting “wheels.” Getting the correct wheeled device for the user is important not only from a financial point of view but also, and especially, from a health and well-being perspective. The wrong device can be harmful physically and well as can affect the motivation to use it. So, here are some things to consider when getting “wheels:”

- **Find out up front what your DME (Durable Medical Equipment) part of your insurance covers**—Check with the customer service representative of your medical insurer before ordering a chair/scooter to see what the procedures and the limits are on getting a chair/scooter. It pays to know this before going to a vendor so that you will not have any surprises and will know what is covered and what you have to pay for. Also, if they need a prescription or letter of medical necessity from your doctor up front, then you can have all of your insurance ducks in a row before going to the vendor, and you don’t risk having your claim delayed or denied. Also, make sure that your doctor has the right processing code as an error will delay payment.
- **Know your goals and your limitations**—before purchasing a wheeled device, ask yourself what your goals and limitations are in relation to what you are getting. Look at such factors as how and where you want or need to use the device. Assess your ability to get into and out of the device and what you will need to access it. Look at the long term, particularly in making a decision about getting a scooter or a chair, and think about what your physical capacity might be in the future. Medicare recipients need to look especially at the long term because benefits for chairs are available only once every five years.
- **Know your vendor and the range of the products that are available**—There are many durable medical equipment vendors and products, not only in cities but also on the Internet. When shopping for vendors, be sure to assess your comfort in working with the vendor because you don’t want to feel pressured into buying something that does not fit within your needs and your goals. Also, there are many bells and whistles available for the various choices and it helps to know which ones are necessary for you and which ones you can live without or not need at all.
- **Learn about follow-up and repairs before you purchase a chair or scooter**—Different vendors and chair/scooter companies have different policies regarding follow-up

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Being an Informed Consumer

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and repairs so it makes sense to ask questions before ordering a chair from a vendor. This is particularly important if you are being fitted with a custom wheel chair. Questions to ask include: What is the policy on follow up? What happens if the chair/scooter does not fit to my satisfaction and meet my needs? Do I have to pay for modifications on the original chair and, if so, within what time period? How much follow-up and modification is allowed before the client has to pay for further modifications? Can repairs and modifications be done in my home or will my chair need to go to the shop to be repaired? If my chair needs to go to the shop, do you have a replacement loaner policy until the work is done? How long does the warranty last? These are just some of the question to ask.

By being an informed consumer you can prevent what could potentially be a nightmare experience and can look forward to many years of improved mobility.

News of Note--

Networking and The Colorado Post-Polio Connections Directory— A Questionnaire was sent out about NETWORKING in the last Connections Newsletter. 15 were returned. (We believe 3 is enough to form some kinds of networks!) However, we regret putting a deadline on it, so if any of you wish, you can still return it. We have good potential for setting up a Directory of People with PPS along with their contact information via phones, mail, & computers. And, there is interest in engaging each other with phone calling, sharing emails, resourceful websites, and even blogging!

We found many were interested in “pitching in” to help with the set ups and even someone who can teach the rest of us how to blog! So, let us know if you are interested and you’ll see more details in Connections soon.

Persons wishing to have their names in a directory sponsored by the Advisory Council and who have lost their questionnaire can still provide their name, address, phone number and email, or any part of that information they wish to be published to Nancy Hanson, 303-233-1666, ext. 237, nhanson@eastersealscolorado.org. The directory will only be sent to those who submit their names to be included and is intended as a resource for those people who want to have peers to communicate with regarding their polio. This can be especially helpful for those polio survivors who are isolated due to distance or mobility issues and who want to be connected with others.

And By the Way . . .

This issue of the Connections is borrowing a feature from Post-Polio Health International for our regular And By the Way . . . column.

Polio Survivors Ask . . . Nancy Baldwin Carter, BA, M. Ed. Psych, Omaha, Nebraska, (n.carter@cox.net)

Q: *We have known about the late effects of polio for almost 30 years. I've gotten a lot of advice during that time and wonder about other polio survivors. What's the best post-polio advice you ever received?*

A: I've always felt I got wonderful advice from Dr. Ann Bailey at Warm Springs. My body had hit a patch of frightening paralysis, and I called her to cry on her shoulder. After listening to my weeping and wailing for quite a while, she finally said, "Accept it, Nancy." These simple words gave me the serenity I needed to go on. No amount of teeth gnashing could help me in the way that accepting the reality of the situation did. This is lasting help—I use her words of wisdom often.

But this is a question with a million answers. I wondered what others would say. Curiosity caused me to contact a number of polio friends around the country to get their responses. From Illinois, Jan says, "Rest. Schedule it into your day. It's as important as anything else you may do and will possibly give you the oomph! to do what you must." "The best advice I've ever gotten is 'walk the knife-edge: too much exercise can hurt you and too little exercise can debilitate you,'" says Larry in Minnesota. "Just in case you're interested, the second best advice was 'take charge of

your own health care.' Certainly that does not mean ignore the advice of your health care professionals but it does mean make sure you understand their recommendations and that those recommendations fit with everything else you know. If they don't, it is your responsibility to question the provider until you do understand." What popped into Becky's mind in Texas is "PACE YOURSELF."

Conserve energy—stop along the way when we need a rest from walking; stop to admire a rose halfway up the staircase. This reminds me of a favorite quote from Georgia O'Keefe: 'Nobody sees a flower really; it is so small. We haven't time, and to see takes time—like to have a friend takes time.' I am encouraged to enjoy the precious things in life, and that doesn't require physical energy." Richard, in California, tells us "You must acknowledge to yourself that you have a disabling condition. Don't be consumed by that reality, but be honest with yourself. Ignoring or denying this reality leads to anger and frustration. It can also lead to counterproductive behaviors. When you make peace with your body you can begin to make appropriate adjustments.

And, don't be afraid of all the things available to assist you in life. These assistive devices can be your friends, not your enemies." "In looking back, the best advice I received was that when judging my activities and exercise, I should be aware that there is weakness from disuse as well as from overuse," says Missouri's Joan. "Pace myself," Peggy, another Missourian, replies. "I must be a hard learner, because on the good days, I find myself trying to do more to sort of catch up with things I was unable to do on the bad days. I call it 'Hallelujah I'm

healed' syndrome, on the good days, and it drives my husband nuts! I try to be good, I really do. But there is a little voice inside that says 'Go for it Peggy. You'll be able to do all of it, and then rest.' I can tell you with certainty that life at our house is not boring."

Aren't these terrific! Now I'm thinking many of you have gotten excellent post-polio advice, as well. Why not share these gems with us—send them to info@post-polio.org and we will post them on www.post-polio.org <<http://www.post-polio.org/>> . *Nancy Baldwin Carter, B.A., M.Ed.Psych, from Omaha, Nebraska, is a polio survivor, a writer, and is founder and former director of Nebraska Polio Survivors Association.* Source: Post-Polio Health International (www.post-polio.org <<http://www.post-polio.org/>>)

A Unique and Inspiring Couple

By Jim Oxley

What a unique and inspiring couple! They both contracted polio in their teens and were primarily paralyzed in their legs. They both came from rural areas in Colorado, one born in Bennett and the other in Loveland. There were no other family members who contracted polio.

This story is about JoAnne and Victor Beebe Jr., who live in a beautiful ranch home at the edge of Loveland. The home was built to meet their needs by Vic's father and some sub-contractors and finished by Vic after their marriage in 1964.

JoAnne was fourteen when she contracted polio during the epidemic year of 1946. She was taken to Children's Hospital

in Denver and put in isolation for nine weeks. Later she was moved to a ward with other children, and her life improved. After that she transferred to the Spears Chiropractic Hospital, also in Denver. She slowly improved from being prone to being able to sit up. Massage was the only therapy available, as no swimming or hot-water facilities were in the hospital. She then returned to her home in Byers where her mother and two sisters cared for her. She remembers the hot packs her mother administered.

Later she spent 9 months at St. Anne's Convalescent Home, operated by the Episcopal Church, and was taken to Children's twice a week for water therapy which was the highlight of her week. There she bonded with Sister Patricia who told JoAnne that "she would probably never walk again . . . but there are more important things in life than walking." She has always been confined to a wheelchair.

Living somewhat in isolation in a small community and away from any trained therapists, JoAnne's parents eventually sold the farm and moved to Denver, where she could get needed therapy and she could interact with other children in school. She taught herself typing and bookkeeping and passed her GED with flying colors. This big accomplishment helped her find jobs. Her first paycheck came from working part-time at Craig Rehab Hospital where she received \$25 per week. After a while, she was employed by Becker Brothers and then employed by Honeywell. She made many friends among the disabled community and at work. And, her life continued to improve.

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A Unique and Inspiring Couple

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Vic came down with polio after he graduated from high school in 1951. He lived with his folks, who ran a dairy farm. Before he had polio, he milked cows, ran machinery and helped his family with anything asked of him. After polio, he was unable to do any of these activities. He tried leg braces but they kept breaking.

By 1954, Vic realized he couldn't farm any more and decided to find another career. A magazine ad led him to a correspondence course in basic electronics and television repair. That training resulted in his starting "Vic's Radio and TV Service." The business grew to a point that his bedroom workshop was too small. Fortunately, his sister had left home so he moved to her bedroom. He also convinced his dad that her could run a tractor with some special attachments to the clutch and steering apparatus. They fabricated these, and he drove tractors for years later.

In 1955 Vic and his parents decided to try therapy at the Spears Chiropractic Hospital, where massage, hydro- and physical therapies were administered to Vic. Some improvement in his lower body occurred; but perhaps, more importantly, Vic benefited emotionally by gaining more self-esteem and losing his shyness. He made many friends there as well. Soon he passed his driver's test, purchased a station wagon to haul TVs, and his dating career flourished.

With so much in common, including a deep religious faith, JoAnne and Vic were introduced to each other through a friend of

JoAnne's. They corresponded, and soon Vic was driving to Denver in a new station wagon to see JoAnne. The romance blossomed and in 1964 they were married. For a wedding present Vic's dad gave them a lot on the farm where they could build a house. They planned and designed it themselves so that it would accommodate their disabilities. Vic made sure he had a repair shop, so they added that to the house. His business grew so large and so fast and became so stressful that he decided to sell his business and find a job that was less demanding. At the time, the Hewlett-Packard company had plants in Fort Collins and Loveland. Vic found employment there and worked in supervisory capacities in both plants over the next twenty years, retiring in 1993.

In 1965, they were blessed with a child, Jeffrey, who brought great joy as well as challenges to their lives. During those years, the Beebes found that a van was their best means of transportation. Appropriate lifts and lockdowns for their wheel chairs were added. They traveled widely and visited family and friends from coast to coast. Since retirement they have become advocates for improving access to buildings in Larimer County, serving on Boards and Committees in the communities. Vic served many years on the Disabilities Resources Services Commission. They attend the Fort Collins/Loveland Polio Support Group on a regular basis. Vic and JoAnne are an inspiration and challenge to us all.

Adapted from an interview with the Beebes and the book of their lives, Wheel Tracks in the Sands of Time, August, 1996.

News of Note--

The Warm Water Therapy Pool at Easter Seals—The pool has been remodeled with a new deck and windows to give it a “spa” feeling. The pool temperature is between 93-94 degrees, and the depth goes from one to four feet. It is handicapped accessible having both stairs with a handrail and a lift.

The work on the electrical system was done at a nominal fee by Bob Hood, owner of Bright Electric in Aurora CO 303-877-0635. Bob is a polio survivor. Thank you, Bob. We appreciate your work and will remember you in the future.

With enough people (5 or more) Easter Seals could create a once or twice a week post-polio class for therapy and for socializing. There are individual/family memberships available or pay as you come fees. Persons interested in following up on this service and for more information can call Tracie Wickham, pool director at 303-233-1666 ext. 1.

Persons who are in need of financial assistance to use the pool can let Tracie know when they call for further information. If there is enough of a need expressed, then the establishment of a grant or scholarship program can be considered.

The Colorado Post-Polio Connections would like to thank the following volunteers who help with the writing, proofreading and mailing and have made this newsletter possible:

Gloria Aemmers, Vada Cary, Jeanine Ellison-Fisher, Delores Glader, Dan Gossert, Barbara Lundstrom, Barbara Nickelson, Karen O’Brien, Jim Oxley, Paul Puma, Ileta Smith, Eleanor Spence and Woody Trosper.

**Marny Eulberg, M.D., Medical Advisor
Nancy Hanson, Easter Seals Colorado
Marlene Harmon, President, Advisory Council
Margaret Hinman, Editor**

This Is Your Newsletter-----

Colorado Post-Polio Connections is a newsletter by and for polio survivors, their friends and others who are interested in being part of our network. The editors and staff invite your contributions to the newsletter. If you have comments, articles, or suggestions for topics for future issues, please email us at post-poliocolo@comcast.net or write to us:

Colorado Post-Polio Connections
Easter Seals Colorado
5755 West Alameda Avenue
Lakewood, Colorado 80226

Please include your name, address, phone number and email address in any correspondence. To change mailing information, contact Nancy Hanson at 303-233-1666, ext. 237 or email her at nhanson@eastersealscolorado.org.

Our next issue will, at least in part, focus on some of the highlights of Post-Polio 10th International Conference, “Living with Polio in the 21st Century.”

Disclaimer

The opinions expressed in this newsletter are those of the individual writers and do not necessarily constitute an endorsement or approval by Easter Seals Colorado or the Post-Polio Advisory Council. If you have personal medical problems, consult your own physician.

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BLIND OR HANDICAPPED**