
◆ THE DERBY CITY NSCIA NEWSLETTER ◆

JUNE 2004

The Derby City Chapter of the National Spinal Cord Injury Association Network- Serving Kentuckiana.

Message From the President

Dear Members & Friends-

In lieu of this month's meeting we will have our annual dinner at Kingfish River Road in Louisville on June 21 at 6:30. Meals will be paid for by the Chapter for all of those who are current dues-paying members. Hope to see you there!

July's meeting will be held at Frazier Rehab, 4th floor dining room. Social hour: 6:30; speaker at 7:00 p.m. Refreshments provided.

- David Allgood

The following IS from SCI Life, October 2002

THE AXIS MODEL: A DISABILITY-FRIENDLY APPROACH TO MANAGED HEALTH CARE

By John Tschida and Chris Duff

No matter where you live, the health care system in the United States is complex and difficult to navigate. This dysfunction is experienced by most everyone, though it is often magnified for people with physical disabilities. Most people with physical disabilities are generally able to find good, competent providers. The challenge lies in being able to access them when needed, to obtain approval for the services or medical equipment in a timely manner, and to make sure the lines of communication among providers remain open so the overall needs of the consumer are met. In Minnesota, a program has been designed to meet the unique needs of people with physical disabilities. While many managed care organizations have 'care coordinators' or 'case managers' charged with linking consumers with the services they need, what they often lack is expertise in disability issues. AXIS Health care is an organization specializing in disability.

WHEELCHAIR COLLECTIONS!! SEE CALENDAR FOR DETAILS.

It was founded by two local leaders in the rehabilitation industry – Courage Center and Sister Kenny Institute. AXIS doesn't provide health care services. It empowers people with disabilities to make choices about their health care services and helps cut through red tape to coordinate the unique needs of each consumer with a disability.

Throughout the United States, there are dozens of Medicaid managed care programs that have enrolled people with disabilities. The problem is that while these programs may include people with disabilities, most are not designed for and with people with disabilities. AXIS, with grant support from the Robert Wood Johnson Foundation, worked with consumers in a pilot project for over two years to build the program model. The goal was to build a quality organization people wanted to join, not a mandatory managed care plan people had to join. The starting point – and the best health care consultant – was the customer. AXIS provided health coordination services on a voluntary basis for over 40 individuals. The participants voiced their expectations, designed their own care plans, and identified their preferred health care providers. More importantly, they expressed their frustration with existing delivery system and recommended changes and opportunities for improvement and efficiency. While AXIS can't fix the entire health care system, it can change the way individuals interact with it, and it can help put the fragments together on behalf of its customers. The goal is to have doctors view their

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Derby City Area Chapter
of the
National Spinal Cord Injury
Association

ABOUT THE ORGANIZATION

The Derby City Area Chapter of the N.S.C.I.A. is a membership organization for individuals with spinal cord injuries, their families, and health professionals. Founded in 1984 as a Charter Member of the N.S.C.I.A., it was incorporated under IRS Section 501 (c) 3 as a not for profit organization. The Board of Directors consists of the Officers, Past President and the Board Members At Large.

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NSCIA
DERBY CITY CHAPTER
NEWSLETTER

Editor- Barbara Davis

Contributor- David Allgood

THE AXIS MODEL, CONT'D

as individuals with differing needs rather than as a conglomerate of symptoms produced by a disability.

Together, AXIS staff and the pilot participants built interest in this new model, engaging key providers, demonstrating that obtaining the right care or service at the right time is primarily the result of coordination rather than increased dollars. In fact, we strongly believe that there is plenty of money in the system now serving people with disabilities. The problem is that the rules haven't allowed for the flexibility to spend it in the right places at the right time.

All health care is local, meaning that significant change in health care services requires the engagement of the consumers, their providers, and payers. In Minnesota, AXIS Healthcare and the pilot participants have been working with Ucare Minnesota (and its extensive provider network), and the Department of Human Services to build a better system. Ucare Minnesota is a managed care organization created to serve persons with Medicaid and Medicare. With almost 100,000 members, they bring extensive experience in managed care and a commitment to flexibility in meeting the needs of persons with physical disabilities. The Department of Human Services, serving as the state Medicaid office, has understood that the existing fee-for-service system has created 'islands of care' with minimal integration of services and supports.

Together, AXIS Healthcare, the pilot participants and other consumers, Ucare Minnesota and the state created Minnesota Disability Health Options program. This voluntary managed care program started accepting enrollment in July 2001. It is available for adults with physical disabilities on Medicaid, with or without Medicare, residing in the Twin Cities Metropolitan area. AXIS is staffed by health and resources coordinators with extensive experience working with persons with physical disabilities and their providers. Each member participates in initial assessment and develops a service plan prior to final enrollment. The member, his or her primary care physician and health coordinator function as the core team in managing the full range of services and supports they need. AXIS staff are available 24/7, and focus on early intervention and risk prevention strategies. Those who join AXIS are not cases to be managed; they are partners in the process. They can also leave the program at any time, making consumer satisfaction a top priority for AXIS. But history and program development only tell part of the story. The best way to describe AXIS is through the people who live and breathe it – people like Gary Madson.

(Continued On Page Four)

Refrigerator Calendar

*2004

JUNE

7th - Elderly & Disabled Advisory Council Meeting

Mon 1:00-2:30 p.m.; TARC; 1000 W. Broadway; Board Room.

21st - NSCIA Derby City Area Chapter meeting; 6:30 p.m.;

Mon Kingfish, Zorn Avenue and River Road.

19th - Metro disAbility Coalition Meeting; 1 p.m. – 3 p.m.; PVA Office on Goss Avenue.

Sat Speaker to be announced; if questions, contact Terri Leasor at 589-6620 or at mdclouky.org

19th City-wide wheelchair collection for The Mobility Project; 10:00 a.m.—3:00 p.m.

Sat John E's Restaurant.; 3708 Bardstown Road. Wheelchairs & other mobility aids are collected and distributed in other countries. If you have questions call Jenny @ 742-6946 or email her @ jsmith@mobilityproject.org

15th Louisville Metro Sweep for Access

Tues Crescent Hill Library; 2762 Frankfort Avenue

JULY

5th - Elderly & Disabled Advisory Council Meeting

Mon 1:00-2:30 p.m.; TARC; 1000 W. Broadway; Board Room.

19th - NSCIA Derby City Area Chapter meeting, 7 p.m., Frazier Rehab.

Mon 4th floor dining hall; speaker to be announced.

17th - Metro disAbility Coalition Meeting; 1 p.m. – 3 p.m.; PVA Office on Goss Avenue.

Sat Speaker to be announced; if questions contact Terri Leasor at 589-6620 or mdclouky.org

For More Information Call
David Allgood, 502-589-6620

THE AXIS MODEL, CONT'D

After experiencing a severe illness, Gary found himself in the hospital for a month, slowly losing control over his life. The doctors around him were making decisions for him, ultimately telling him he needed to be placed in a nursing home.

Through talking with his doctor, Gary learned about AXIS, and was soon connected to Sue Bulger. As he and Sue worked together over the following months, Gary was able to regain his health, acquire financial assistance, receive equipment for his health needs, and return to his job. Instead of going to a nursing home, he returned to his own home.

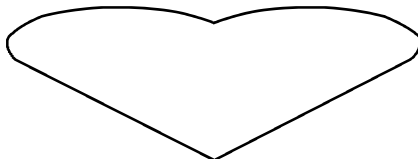
A main problem that Gary recognizes in the health care system is the enormous amount of red tape people with disabilities have to endure in order to get what they need. He explained that Sue was a great advocate for him in the system and allowed him to by-pass the red tape involved in getting assistance. "I like the fact that they're straight with you," he said as he referred to his relationship with Sue. "The system is too complicated. AXIS has people who know the system and help to change it"

Furthermore, AXIS was able to do for Gary what no one else had yet done. Simply, AXIS asked Gary what he wanted to do instead of telling him what to do.

Through knowledgeable and experienced experts in the health care system, AXIS is able to coordinate a results-oriented, cost-efficient, and timely health plan for its consumers. More importantly, AXIS allows consumers to control the decisions they make in regards to maintaining healthy lives.

Both Sue and Gary share the belief that AXIS places great stress on building relationships with their consumers. Through trust and communication, Sue believes that AXIS can give the right kinds of medical attention to people with physical disabilities. "I think we can, one-by-one, make life better for people."

Life is definitely better now for Gary. He lives independently without the intrusion of people making decisions for him. "When you can focus, it makes all the difference." His focus can be on other things – such as preparing for his son's marriage.



From New Mobility, December 2003

HOW TO DEFEND THE ADA

By Amy Robertson

I am writing in response to your article, "Who Lost the ADA?" (September 2003). It was an excellent overview with excellent suggestions for activism. I write to offer a single perspective on the status of the ADA and two specific suggestions for what readers can do about it.

My perspective is that of a lawyer whose practice is devoted to the ADA. While the Supreme Court has been hard on the ADA, Supreme Court decisions on other civil rights laws and lower court decisions on more obscure procedural issues have been far more destructive.

Following the Supreme Court's ADA decisions—even if we lose *Tennessee v. Lane* and even if Title II (the ADA section that applies to governmental entities) is held to violate the constitution—we can still bring lawsuits under Title I (employment) and Title II. The only thing Garrett (and Lane, if we lose) prevent is lawsuits for damages against state. So if your Title II lawsuit is against, say, the local public transit agency, it will be unaffected by the Garrett or Lane decisions.

Even if your claim is against the state itself, you can still file a lawsuit to make the state change its behavior—provide an accommodation, install a ramp, modify discriminatory criteria—you just can't ask for damages. The worst Garrett and Lane can do is make Title I (against a state) and Title II more like Title III (public accommodations): you can sue to change behavior, but not for damages. Not great, but certainly far from fatal.

Far worse are the Supreme Court and lower court decisions on such eye-glaze-over topics as standing, mootness, class actions, private rights of action, and the catalyst theory of attorneys' fees. Boring as these topics may be—how much easier is it to rally support with the headline, "Supreme Court Declares Title I Unconstitutional" than with "Supreme Court Rules Catalyst Theory Unavailable" - decisions on these topics severely restrict the ability of people with disabilities to get into court in the first place. They also restrict the ability of disability advocacy organizations to bring ADA claims and the use of class actions as a device to make systemic change.

These decisions are going the wrong way for two reasons: lawyers are not doing their homework and therefore bringing claims that are easily attacked; and judges who are hostile to the ADA. There are simple solutions to both of these problems.


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HOW TO DEFEND THE ADA, CONT'D

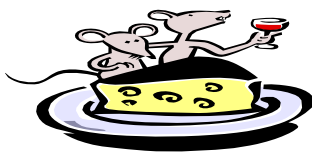
The solution to the first problem: Make your attorneys do their homework! You can almost always posture a case so that it avoids the pitfalls of standing, mootness, and class certification. Do this and you will save people with disabilities from the effects of bad decisions. If you don't have the resources or experience, network with other ADA lawyers or organizations. I love what I do and enjoy nothing more than sharing ideas and resources with other activists and lawyers. We also put many sample pleadings on our website, feel free to download: www.foxrob.com/pleadings/pleadings.htm.

The solution to the second problem: Vote for Democratic candidates for senator and president. I realize that's partisan; it's also reality. Federal judges—who make most of the ADA and other civil rights decisions—are nominated by the president and confirmed by the Senate. President Bush, despite his rather moderate record on disability rights, has consistently appointed judges with an express hostility toward civil rights. Republican senators, no matter how admirable their views in other areas, have voted along their party line to confirm these judges. Decisions handed down by these judges are the ones that, day-to-day, chip away at the ADA and other civil rights protections.

Even if you are a Republican and/or your political views tend to the conservative, if you believe in disability rights, consider voting for a Democrat for president and in your local Senate elections in 2004. If you are an independent or a Green and find yourself with qualms about both parties, consider exercising your independence or giving voice to your qualms at the local level, and voting Democratic for senator and president. Most importantly, if you are a Democrat, just get out and vote.

In the long run, the  appointment of federal judges who understand civil rights is the only hope for the future of the ADA.

The above is opinion of The NSCIA partisan



solely the the author. is not a group. Ed.

FOR SALE!!!!**

- ***2003 Ford F-250 lift-equipped green/gray van;** leather seats, TV, DVD, cd player, Playstation hookup, am-fm radio. Rick Miller, 937-2245.
- ***Shower Chair;** 2 yrs old; negotiable; **2 RoHo cushions;** low profile; \$150 each; **Invacare 900 Action power chair;** 4 yrs old; \$600. Call 448-5296.
- ***Ro Ho high profile 16x16 cushions;** \$160; 589-6620.
- ***Wheelchair;** 20" wide; adjusted petals; standard wheels; asking \$2,2500. **Quickie wheelchair;** 19" wide; asking \$2,000; needs batteries. **New bedside commode;** used; \$75.00. Call 502-636-4043.
- ***1984 Dodge Ram;** handicap conversion; Crow River lift w/exterior/interior controls; heightened roof/door; captain chairs; exchange driver's seat; hand controls; AC; AM/FM cassette & CB radios; wheelchair lock down/ties; rear bench; 2 spare captain chairs; 86,584 miles; good condition. Call 859-734-6852.
- ***2002 Dodge Caravan "Entervan" (Braun modification);** app 18,000 mi; remote operated oil recently changed; mechanic confirms excellent condition; used only a little more than 2 mos.; \$34,000. Call 859-492-7971.
- ***Ford 1997 Econoline Van;** 100,140 mi; \$16,000. Hunter Green-gray; new tires & brakes; "loaded"; call 270-786-4547; ask for Dale.
- ***1994 Dodge Caravan,** equipped with lock down for driving; cruise control; tinted windows; 56,000 miles; good condition; \$14,000; contact Ina Hogan at 241-7849.
- ***Hoveround MPV4;** used only one year; 36" long; 23 1/2" wide; load capacity 300 lbs.; two direct drive motors; turning radius 17"; speed 5 mph. Asking \$5,000 or best offer. Call 671-7656.
- ***Jazzy Electric Wheelchair;** \$2,000; 812-867-0137.
- ***1985 Komfort Koach Van with Power Lift;** V-8; 350 BB; 5 liter engine; wheelchair safety straps; hook; television; power window and door locks; 127,000 mi; excellent condition; new tires; AC/front and rear vents; cruise control; AM/FM radio; tape deck; CB radio; game table and window shades; trailer hitch. \$2,995. 425-0314.
- ***Heavy Duty Scooter;** used less than 50 hours/2 new batteries; \$1200. Call (502) 348-9305.
- ***Liberty Stairlift/Set up for 13 steps;** \$1500 soft; 937-9492
- ***Video tapes for sale.** Various topics related to spinal cord injuries. Call David Allgood or Buddy Lawson.

****If assistance is needed to pay for any of the above items, contact Kentucky Assistive Technology Loan Corporation at for information on loans at 5% interest to qualified candidates.*

