



IOWA NEWS

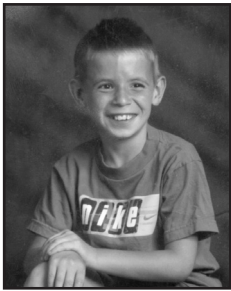
SUMMER 2010

Family's Advocacy Results in New Law

Tanner Wilson was 11 when he died in a prone restraint that is banned starting today.

By Clark Kauffman – ckauffman@DMREG.COM – July 21, 2010

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Tanner Wilson was 11 years old when he died, pinned to the floor of an Iowa care facility for children with behavioral disorders.

Today, more than nine years later, a new regulation inspired by Tanner's death becomes state law. It prohibits the use of certain types of physical restraints in Iowa's psychiatric care facilities for children.

For Tanner's mother, Karen Wilson, today marks the culmination of several years of effort to improve the care and protection of institutionalized children. She describes it as a "long journey" that began on Feb. 9, 2001, at the Gerard of Iowa home in Mason City.

Workers at the privately run home were holding Tanner facedown on the floor, trying to subdue him. Gerard officials said the boy stopped breathing after the workers placed him in what the company called a "routine physical holding."

The county medical examiner classified Tanner's death as a homicide – a term that indicates another person has contributed to an individual's death, though not necessarily through negligence or criminal acts.

One of Tanner's caregivers was charged with child endangerment, but the attorney

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Iowa P&A to Change Name October 1st!

The Iowa Protection and Advocacy Services Board of Directors has some very exciting news! At its April and June meetings, it decided to change the organization's name. Beginning October 1st, Iowa Protection and Advocacy Services, Inc. will become **Disability Rights Iowa**.

Disability Rights IOWA

Protection & Advocacy for Individuals with Disabilities™

"We're changing our name for a couple of reasons," says Lesa Niday, President. "Our new name better expresses our mission and what we do. Also, it describes who we serve." Since 2000, 18 protection and advocacy agencies across the United States have changed their names to "Disability Rights." Iowa is joining that trend to promote consistency and access to advocacy services.

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Iowa P&A Participates in RAGBRAI XXXVIII

Braving the 4 H's – heat, humidity, hills, and headwinds – members of Team IPNA (also known as Team PandA) successfully completed a three-day trip on RAGBRAI – the Register's Annual Great Bicycle Ride Across Iowa. Beginning Tuesday morning in Algona, the ten team members ended their journey in Parkersburg on Thursday. Opportunity Village graciously hosted Iowa P&A's team on Tuesday evening in their gymnasium – a welcome shelter from the rain.

In addition to having a great time, Team PandA promoted voter accessibility and awareness of Iowa P&A services. "It was a lot of fun," says Steve Garrison, Iowa P&A Advocate/



Team PandA

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general declined to prosecute the case.

After Tanner died, Karen Wilson served for six years on the board of Iowa Protection and Advocacy Services, the congressionally chartered agency that advocates for the disabled in Iowa.

"I wanted to get involved in an advocacy group because it was a way to channel my grief and try to do something positive for children," she said. "I learned through that process a lot about what is really going wrong in those facilities as far as restraint deaths that aren't publically reported – deaths that we don't hear about."

Prone restraints – the act of immobilizing a person facedown with one or more people pinning down the individual – have been blamed for 48 juvenile deaths between 1998 and 2006. The federal Government Accountability Office said about 10 states have banned prone restraints in various institutional settings.

Last fall, Karen Wilson met with Dean Lerner, director of the Iowa Department of Inspections and Appeals, the agency that regulates many of the state's care facilities. She told Lerner that for years she had been hoping Iowa would prohibit the use of prone restraints in its privately run children's psychiatric facilities.

"And I told Dean that I just didn't know where to go with that issue," Wilson said. "Now, he could have just said, 'Well, good luck with that.' But he didn't. He told me, 'I'll set up a meeting with my staff and we'll see what we can do.' And that's were everything took off."

The department drafted new administrative rules to ban the use of prone restraints in psychiatric facilities for children. During the process of approval, public hearings were held and no industry officials spoke in opposition to the change.

Kathryn Power, director of the Federal Center for Mental Health Services, called the change "an outstanding victory for the well-being of children in Iowa."

The state already had banned the use of the prone restraints in schools, state-run care facilities and prisons. But even with the change that takes effect today, there still will be 150 residential facilities, children's shelters and detention centers that are overseen by the Iowa Department of Human Services but not subject to the ban.

Department spokesman Roger Munns said the agency has notified those facilities that DHS is preparing rules that will prohibit the use of prone restraints. Those facilities, Munns said, appear to have voluntarily banned the use of such restraints through their own internal policies.

"If permitted at all, its use does not appear to be widespread," he said. "But we need to formalize this policy and make it as universal as possible."

Not long ago, the Massachusetts Department of Mental Health asked Karen Wilson and her husband to participate in a documentary on the dangers of restraints.

As part of that project, the filmmakers created an age-progressed photo illustration of what Tanner might look today as a young man.

For the Wilsons, the photo represents a heartbreaking glimpse of what might have been.

But it also serves as a reminder of what's at stake in their effort to ban the use of prone restraints.

"This has been a long journey," Karen Wilson said. "My goal and my husband's goal was to make sure this would never happen to another family." ■

BE SURE TO VOTE – TUESDAY, NOVEMBER 2, 2010!!

This year is a BIG election year for Iowa. Voters will decide who will fill important offices, including:

U.S. Senator	Secretary of Agriculture
U.S. Representative	Attorney General
Governor and Lieutenant Governor	State Auditor
Secretary of State	State Treasurer

Elections for your State Senator or State Representative depend upon the district in which you live. There may be county, city/town, and school elections, too.

If you have questions or concerns about your voting experience – either registering to vote, accessing your polling site, casting your vote, getting assistance at the poll site, or other issues – please call Iowa Protection and Advocacy Services at 1-800-779-2502 or toll free TTY at 1-866-483-3342. You may also call your local county auditor or the Secretary of State office at 515-281-0145.





Iowa P&A Hosts Seminar on Self-Inflicted Violence



On June 15, 2010, Iowa Protection and Advocacy Services Inc. hosted a seminar entitled *Self-Inflicted Violence: Complex Problem, Simple Solution*. The event was held at the Iowa Medical and Classification Center, Oakdale Prison in Coralville, Iowa.

Ruta Mazelis, a recognized expert on trauma, conducted the training.

Ms. Mazelis edits *The Cutting Edge: A Newsletter for People Living with Self-Inflicted Violence*, an internationally distributed quarterly on the topic of self-injury. She is experienced in providing services in mental health and substance abuse programs as well as inservice training, policy development, and research. She is on staff with the Sidran Institute and Witness Justice, serves on the board of the National Trauma Consortium, was a program manager for the National Center for Trauma-Informed Care, and serves as a consultant to various projects at local and federal levels.

The training explored the meaning and purpose of self-injury, a commonly misunderstood aspect of many people's lives. Etiology, diagnostic implications, and treatment strategies were discussed, as well as the special circumstances that arise from working with those who self-injure.

Participant goals in the workshop were to:

- Gain an understanding of the multiple perspectives on the etiology of self-injury, including addiction, trauma, and biopsychiatric theories.
- Identify common misperceptions regarding self-injury and become familiar with the many meanings and motivations associated with the act of self-inflicted violence.
- Become sensitized to individual variances in the function of self-inflicted violence, and gain insight into cultural and environmental influences.
- Identify treatment practices that are either ineffective or harmful to persons living with self-inflicted violence.
- Become familiar with therapeutic approaches that facilitate healing from self-inflicted violence.
- Identify multiple stressors arising from clinical work with persons who self-injure.

"Self-inflicted violence is a very difficult subject, and it is important that direct caregivers and professionals have an adequate understanding and sensitivity toward individuals who live with this disability," said Sylvia Piper, Iowa P&A Executive Director. "It was important for Iowa P&A to take the lead in providing this special seminar. Hopefully, state agencies will ensure that additional training in Iowa will be available." ■

Did You Know?

Costco, in their publication *The Costco Connection* regularly includes information helpful for people living with a disability. Last April, they included the following information:

CONNECTING THE DISABILITY COMMUNITY

The U.S. Department of Labor has renamed and relaunched its website Disabilityinfo.gov as Disability.gov. The new site integrates content from 22 federal agencies and was revamped with social media tools to encourage interaction and feedback, and offers new ways to organize, share and receive information. Disability.gov is not just for those with disabilities, but also for parents of children with disabilities, employers, workforce and human resources professionals, veterans, educators, caregivers and many others.

In June 2010, Costco published this in *The Costco Connection*:

DISABILITIES [DIS]COUNT

Living with disabilities presents a challenge physically, but the financial burden makes it doubly difficult. Numerous discounts are available for people with disabilities; however, finding them can be a daunting task. David Squar accidentally uncovered one when the demands of his wife Mara's multiple sclerosis forced them to move to a smaller house after their children had moved out.

With the move came a discovery. The county recorder notified them that, because the move was to replace the residence of a person with disabilities, the Squars were entitled to a property tax discount.

"I was in the escrow business for 35 years, owning my own company [and] never noticed that was available." Squar says. "The type on the document is so tiny, you'd never notice it."

That led to more research to see what other concessions existed, and the Squars decided the information should be made widely available. DisabledDiscounts.com (disableddiscounts.com) went live in early 2010. David does most of the research himself, with some assistance from friends finding programs and discounts for the disabled offered by governments and businesses across the United States. Mara hosts a community forum to facilitate discussion among people sharing similar burdens. To help cover the costs of running the site, DisabledDiscounts.com carries a subscription fee of \$25 per year, covering one state; additional states can be added at a reduced rate. ■





We Have Human Rights

The Harvard Project on Disability (www.hpod.org) has published a book for self-advocates called **WE HAVE HUMAN RIGHTS**. The book can be downloaded free of charge from their website, or at www.selfadvocacy.org. It can also be purchased for \$5.00 each at those websites.

Iowa P&A has received permission from the Harvard Project on Disability to print excerpts from their book:

This book is for people with developmental disabilities. You can use it to learn about your rights. You can also use it to talk with others about your rights.

When you speak up for yourself, you are a self-advocate. When you work together with others, you can make change

happen. Welcome to the power of human rights! In the past, people with disabilities have not been treated as equals. That is changing.

In 2007, the United Nations passed a new law. It says people with disabilities have the same rights as everyone else. It says all people with disabilities are equal before the law. It says this applies to women and girls, and children with disabilities, too.

Because we are human, we have human rights. One of these rights is:

Privacy

**We have the right to privacy,
no matter where we live.**

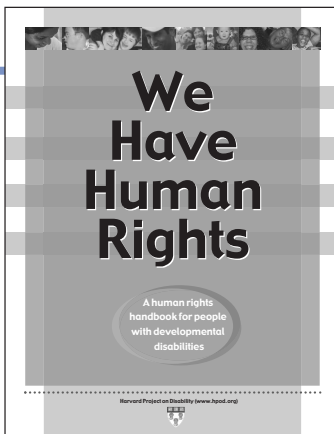
Sound familiar?

Someone is always hovering around when I'm with my boyfriend.

My caregiver stole money from me.

The doctor told my health story to a bunch of strangers in the room.

My helper tells other people all sorts of stuff about me.



What does the new law say about privacy?

What we do in our own room is our business.

We decide what others can know about our lives.

No one can read our letters unless we say it's OK.

No one can listen to our phone calls unless we say it's OK.

We have the right to private space to be with our sweetheart.

Helpers have no right to tell others what they know about us.

The Iowa Protection and Advocacy Services, Inc.,
Board of Directors
invites you to an

**Open house to celebrate our new office space
and our
25th Annual Meeting**

Friday, September 24, 2010

Open House – 3:00 pm to 6:00 pm

25th Annual Meeting – 7:00 pm

400 East Court Avenue, Suite 300
Des Moines, Iowa

Board of Directors:

Lesa Niday, President - *Ankeny, IA*
Scott Ourth, Vice President - *Ackworth, IA*
Valerie Owens, Secretary - *Winterset, IA*
Michael Eide, Treasurer - *Waterloo, IA*
Lynne Hilgendorf, Fifth Member - *Comanche, IA*
Karen Swensen - *Des Moines, IA*
Lois Russell - *Lamoni, IA*
Rachel Dray - *Cedar Falls, IA*
John Winkelman - *Sac City, IA*

A portion of our annual meeting is devoted to a public forum. If you wish to make comments, please contact our office in advance at: (515) 278-2502, 1-800-779-2502 (toll free), or 1-866-483-3342 (toll free TTY).



RAGBRAI XXXVIII continued from pg 1

Investigator, “Although next year I think I’m going to train harder prior to the ride.” Lori Hayden, Executive Assistant, wants to ride next year, and Jon Doidge, Development Consultant, noted, “All RAGBRAI riders are equal. That is, whether you pedal fast or slow, use an adapted bike or speedy titanium one, you all share the goal of doing your best and respecting your accomplishments.”



Thousands of RAGBRAI riders coming into Parkersburg on Thursday, July 29th.



TEAM Panda members talked with bikers about voter accessibility and our services. Team members also handed out wet wipes – a welcome gift.



Iowa P&A’s TEAM Panda made a flag to increase awareness and help team members find each other.



TEAM Panda was welcomed by well-wishers Tony and Marsha Gelina along with Tom Laurenzo as the bikers reached Clear Lake on Wednesday evening.



Some TEAM Panda members taking a break to pose for the camera. A total of ten team members participated in RAGBRAI XXXVIII.





ADA Marks 20th Anniversary

Article submitted by Shawna Anderson, Iowa Civil Rights Commission



Blindness didn't stop Mike Hoenig, a Davenport resident, from becoming a live theatre fan. Cerebral Palsy hasn't stopped Nancy Witt from succeeding at her work with the State Public Policy Group, and from being a statewide civil rights commissioner. These noteworthy Iowans are a prime example of how Iowa has benefitted from the contributions of people with disabilities. Their successes are largely attributed to their own talent, ambition, and perseverance, but these Iowans recognize that the Americans with Disabilities Act (ADA) played a role as well.

The ADA is a landmark piece of federal legislation, enacted by Congress and signed into law July of 1990 by President George H. W. Bush. This law affords similar protections to Americans with disabilities as the Civil Rights Act of 1964, which made discrimination based on race, religion, national origin, and other characteristics illegal. It requires housing authorities, employers, and public accommodation providers to make "reasonable accommodations" for individuals with physical and mental disabilities.

This year marks the 20th anniversary of the ADA. Throughout Iowa, the AmeriCorps VISTAs at the Iowa Civil Rights Commission (ICRC) are working with minor-league ballparks, colleges, government offices, disability organizations, and private businesses across the state to sustain year-long ADA recognition efforts. ICRC Executive Director Ralph Rosenberg says of these efforts, "It is appropriate to celebrate and commemorate successes. It is also timely to continue to educate the public on the law and policy. It is also appropriate to point out how the ADA has helped Iowans of all ability levels."

When it comes to the rise in ADA-instituted accommodations over the last 20 years, there is much to celebrate. Mike Hoenig says of his workplace accommodations, "They helped me live more independently." The availability of assistive resources such as a computer with a screen reader, Braille on doors, as well as a personal driver have made it possible for Hoenig to advance his career as Project Manager at the Center for Disabilities and Development. Responding to e-mail is now an ordinary task, just as it would be for a

sighted person. And with the help of his driver, Hoenig freely travels to Iowa's K-12 schools, raising disability awareness in the classrooms. "Without these accommodations, I wouldn't be able to do it," he comments.

There is still, however, much that needs to be improved upon in the 20 years to come, specifically within the area of public accommodations. Every day, new buildings are erected without accessible entrances, restrooms, and stairways. ATMs are routinely installed with no Braille keypads or audio instructions for those with visual impairments. Housing should be designed and constructed, considering 'universal design' while providing reasonable accommodations for tenants with disabilities.

Why aren't people following the ADA? For some, it may be because they are simply unaware of these laws or how to achieve compliance. This year's ADA recognition efforts focus on success stories, and intend to raise the awareness of the law, of areas where we need improvement, and how we can reach our goals in the next 20 years.

When Iowans of all ability levels are included and appreciated, the state as a whole benefits. And that is a goal we should all strive to meet.

If you suspect that you are a victim of discrimination, call the Iowa Civil Rights Commission today. They are a neutral, investigative agency that enforces the *Iowa Civil Rights Act of 1965*, Iowa's anti-discrimination law. Although they do not provide legal representation, their specialists will work to resolve your dispute through screening, investigation, and neutral mediation.

If the incident at hand took place in the Des Moines city limits, call the Des Moines Human Rights Commission at 515-283-4284. If the incident took place outside of Des Moines, call the Iowa Civil Rights Commission toll-free at 800-457-4416. Their services are 100% free and confidential.

Shawna Anderson is an AmeriCorps VISTA at the Iowa Civil Rights Commission. Her VISTA project involves facilitating statewide outreach in honor of the 20th anniversary of the Americans with Disabilities Act. For more information on her project, visit www.ada-iowa.webs.com, or contact her directly at Shawna.Anderson@iowa.gov. ■

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"Our mission remains the same," says Sylvia Piper, Executive Director. "We do more than protect and advocate – we help people living with disabilities exercise their rights. Our new name is significant and powerful and will guide us in our future endeavors."

Along with a new name, Iowa P&A will sport a new logo, an updated "look" that will promote our new name. **Look for important changes beginning October 1st!**

Iowa P&A Mission: To promote and defend the human and legal rights of Iowans with disabilities



Implementing the Americans With Disabilities Act – How Does Iowa Compare?

This year, we’re celebrating the 20th year since the Americans with Disabilities Act (ADA) was enacted. ADA is a federal law that makes discrimination against people living with disabilities illegal.

People living with disabilities:

- Have an equal right to live on their own in the community.
- Have an equal right to work, in a job they choose, and to earn a decent living.
- Have the right to an equal education, side by side with everyone else.
- Have the right to the best possible health care.ⁱ

The ADA is all about helping people live successfully in the community, regardless of their needs. It supports inclusion, independence, equality, safety, home and family, access, and advocacy – all those areas that people living without disabilities take for granted as inalienable rights. ADA does not support or condone segregation, “separate but equal,” or equivalency.

In early June, Governor Culver and DHS Director Krogmeier traveled to Glenwood Resource Center, Iowa’s largest institution for people with intellectual disabilities to celebrate ADA’s anniversary. This location was an odd choice, considering that this landmark legislation, authored by Iowa Senator Tom Harkin, was designed to provide further opportunities for people with disabilities to enjoy all the benefits of people without disabilities – to live in the community closer to family and friends, to become involved in community affairs, and to enjoy the benefits of meaningful employment, achievement, and cultural and recreational activities that are available to everyone else.

So, how does Iowa stack up on providing equal opportunities for people with disabilities?

	Iowa’s Percentage	National Average	Iowa’s Rank (1=Best)
Percent of ID/DD Expenditures on non-ICF/MR Services ⁱⁱ	62.8%	76.8%	46 th
Percent of individuals with disabilities in community settings ^v	79.2%	88.6%	45 th
Percent of individuals who live in large settings of 16 people or more ^v	13.2%	5.8%	44 th
Percent of individuals who live in large state facilities ^{vi}	3.9%	3.7%	31 st
Iowa’s rank of community inclusion efforts compared with other U.S. states and District of Columbia ^{vii}			33 rd

Can Iowa do better? Yes!

We must insure that the principles and intent of the ADA, which became law 20 years ago, are fully implemented, not for just a few Iowans, but for all Iowans living with disabilities. We must ensure that the basic rights for *everyone* are respected, and that all our efforts are directed so that all Iowans experience:

- Presence and participation in the richness of Iowa’s way of life.
- Opportunities to develop and exercise individual competence.
- Opportunities to make meaningful choices in the pursuit of personal determination.
- Good relationships with family members and friends.
- Respect and dignity. ■

ⁱ From “We have Human Rights,” Harvard Project on Disability, 2009

ⁱⁱ Rank, compared with other 49 states and District of Columbia

ⁱⁱⁱ Coleman Institute, 2010

^{iv} Research & Training Center on Community Living, 2010

^{vi} Research & Training Center on Community Living, 2010

^{vii} United Cerebral Palsy 2010 Inclusion Report



2010
MENTAL HEALTH CONFERENCE
Reinforcing Recovery and Resiliency

October 5 & 6, 2010
Iowa State Center
Scheman Building
Ames, Iowa

The 2010 Mental Health Conference is designed for professionals, clinicians, administrators, educators, consumers, family members, advocates, and other providers.

Keynote speakers include: Joe Marrone, Institute for Community Inclusion/UMASS BOSTON; Michael Flaum, Iowa Consortium for Mental Health; Nancee Blum, University of Iowa, Carver College of Medicine; Lieutenant Colonel Barb Sutton, Deputy State Surgeon, Iowa Army National Guard; and Richard Berchou, Wayne State University.

For additional information or to register on-line for the conference, go to www.trainingresources.org, or contact Training Resources, 1211 Vine Street, Suite 2230, West Des Moines, Iowa 50265. Telephone: (515) 309-3315.



Iowa Protection and Advocacy Services, Inc.

400 E. Court Ave., Suite 300
Des Moines, IA 50309

"A federally funded program to defend and promote the human and legal rights of Iowans who have disabilities and mental illnesses."

515-278-2502 (Voice)

515-278-0571 (TTY)

1-800-779-2502 (Toll Free)

1-866-483-3342 (Toll Free TTY)

515-278-0539 (Fax)

www.ipna.org

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These materials were made possible by funding support from the U.S. Department of Health and Human Services: the Administration on Developmental Disabilities, and the Center for Mental Health Services of the Substance Abuse and Mental Health Services Administration; and from the Rehabilitation Services Administration of the U.S. Department of Education and the Social Security Administration. The contents of these materials are solely the responsibility of Iowa Protection and Advocacy Services, Inc. and do not necessarily represent the official views of any of these agencies.



Iowa P&A Moves to 400 East Court Avenue, Suite 300 Des Moines, Iowa 50309

After being located on Office Park Road for seven years, Iowa Protection and Advocacy Services moved its offices to 400 East Court Avenue, Suite 300 on May 28th. "The amount of space we have hasn't changed," states Lori Hayden, Executive Assistant, who coordinated the office move. However, the new location really suits our needs better." The new office layout, which includes large and small conference areas, was designed specifically for Iowa P&A. The East Village location is closer to the State Capitol, state department offices, as well as partner advocacy organizations. Physical accessibility has been enhanced, and the new space is more convenient to public transportation, too.

"Our new office location makes us more visible," said Sylvia Piper, Executive Director. "The staff worked hard, not only in cleaning house and discarding surplus items accumulated over the years, but ensuring that our services were not disrupted because of the move."

While the address changed, all other contact information, including telephone numbers and website address, remains the same.



Iowa P&A welcomes you to submit articles or photo ideas for publication consideration in our future newsletters. Examples of ideas include new resources or services for persons with disabilities, how Iowa P&A helped you, things to watch for in disability-related laws, and many others. Submission of materials does not necessarily guarantee publication, and all publication choices are solely at the discretion of the agency. Any materials submitted for possible publication may be edited for content. All original materials can be returned upon request.