


ignite thoughts into action

spark



 Indiana Governor's Council
for People with Disabilities

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in this issue on
HEALTH + WELLNESS



Get in the game:
fitness programs



Advocate lives a
healthy lifestyle



Highlights from the
2010 Conference

in this issue on
**HEALTH +
WELLNESS**

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spark is a bi-monthly publication of the Indiana Governor’s Council for People with Disabilities. An independent state agency that facilitates change, our mission is to promote public policy which leads to the independence, productivity and inclusion of people with disabilities in all aspects of society.

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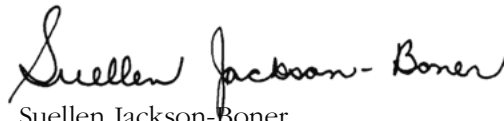
Health care accounts for 16 percent of the United States’ gross domestic product, the highest among the world’s industrialized nations, according to the Kaiser Family Foundation. During the past decade, health care spending has grown at an unsustainable rate, outpacing the growth of inflation and national income.

In 2008 alone, the U.S. spent \$2.3 trillion on health care – more than triple the amount spent in 1990. Furthermore, the number of uninsured Americans has spiraled upward to more than 50 million, according to a September 2010 U.S. Census Bureau report.


The magnitude of the health care crisis forced the nation to ignite a public discussion about the future of our health care system. The product of health care reform – the Patient Protection and Affordable Care Act – has given way to a new perspective of health care in America. The new law emphasizes healthier lifestyles to prevent illness and disease; encourages a strengthened physician-patient relationship that enables patients to take a more active role in their treatments; and provides new opportunities for citizens to influence public policy related to health care at state and community levels.

This issue of Spark addresses health care and general wellness. We hope these informative articles will encourage you to take a preventive approach to your health care and an active role in shaping health care policy.

Sincerely,



Suellen Jackson-Boner
Executive Director



Get in the game: sports and fitness programs for people with disabilities

Now more than ever, as obesity continues to steadily rise across the nation, it's important to be physically active. Throughout Indiana, organizations offer a growing number of adaptive and inclusive fitness programs for people with disabilities. Participation in these programs

health interest can be met by joining a wide range of different programs. Two Indianapolis programs – Positive Swing and Fitness Following Disability – are great examples of the fitness opportunities for people with disabilities available throughout the state.

stairs awaiting ownership. Positive Swing Inc., a registered 501(c)(3) housed within the Golf Dome, is working to get that equipment into the hands of people with disabilities.

“We have the opportunity to work with people who most often stay home. Golf is a nice sport because people talk and have friendships. Golf is a means to an end, and that end is people being more mentally and physically active.”

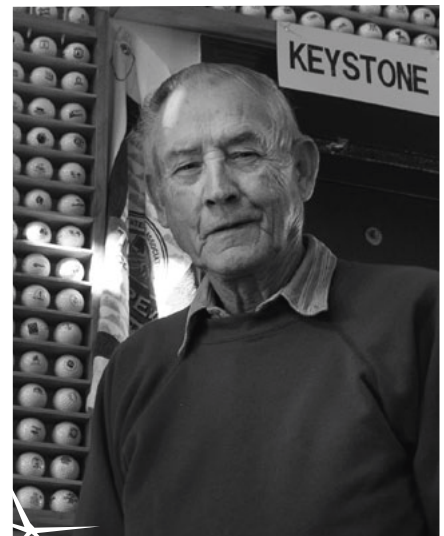
– John Stack, president of Positive Swing

can help individuals get the regular exercise they need to fight the battle against obesity and other health issues.

From general wellness activities to sports teams, nearly any

Positive Swing

The second level of the Golf Dome, an indoor driving range on the south side of Indianapolis, is a sea of equipment. Clubs and bags, new and used, sit at the top of the



Positive Swing President John Stack founded the organization in 2003 to bring golf into the lives of people with disabilities.



Thanks to donations, Positive Swing has an abundance of sports equipment available to visitors.

John Stack, president of Positive Swing and owner of the Golf Dome, founded the organization in 2003 after realizing the potential his 26,000-square-foot indoor driving range had to introduce golf to underserved audiences: people with disabilities and inner-city youth.

Be it lessons, practice space or adaptive equipment, Positive Swing offers programs to fit any need. “We can accommodate people of any age or with any disability,” Stack said.

Stack describes the organization’s services as “heavily discounted and more often-than-not free,” supported by generous private donations and grant funding. “We work at giving things away because so much has been given to us,” Stack explained.

Stack recognizes golf as an outlet for people with disabilities to not only participate in a physical activity, but to also enjoy the social elements the sport offers. “We have the opportunity to work with people who most often stay home. Golf is a nice sport

because people talk and have friendships,” Stack said. “Golf is a means to an end, and that end is people being more mentally and physically active.”

Organizations across Indiana, such as HOOK Rehabilitation and Damar Services Inc., have partnered with Positive Swing to create specialized programs. Recognizing that such organizations could benefit from additional offerings, Positive Swing applied for and received multi-sport zoning in early 2009. This allowed the organization to expand its programming to include baseball, softball, kickball and soccer, among others.

To learn more about individual or group programs, contact John Stack at (317) 786-2663 or johnstackgolfdome@juno.com. The organization is open year-round, seven days a week.

Fitness Following Disability at the Baxter YMCA

Thursday mornings at the southern Indianapolis Baxter YMCA are filled with the buzz of activity. Parents pop in and out, dropping

off children at the daycare center. Participants in an aquatics class can be seen splashing in the facility’s pool. The atmosphere is no different upstairs where participants in the Fitness Following Disability program gather for their weekly class.

Unique to the Baxter location, the program is a partnership between the YMCA and the University of Indianapolis Krannert School of Physical Therapy. Intended for adults who have neurological disabilities, the program’s purpose is to “combine social, leisure, physical activity and wellness into a once-a-week experience.” For 12 weeks, six to 12 participants spend an hour each Thursday with first-year physical therapy students.

The class, led by University of Indianapolis Associate Professor Elizabeth Whalen, P.T., Ph.D., begins with participants seated in a circle. Each participant takes a turn introducing him/herself and leading the group in an exercise. From twenty-somethings to a ninety-one-year-old, the age range varies, as do the ability levels.



University of Indianapolis physical therapy students assist participants with warm-up exercises during the Fitness Following Disability class at the Baxter YMCA.



Fitness Following Disability participants perform a strength-building exercise as part of the 12-week program.

Participants then choose the fitness activity on which they would like to individually focus – be it stretching, biking, walking or weight-lifting – and receive personal training with Whalen or a student through the help

It's something he looks forward to," Harriet Roberts, Ted's wife, said of her husband's involvement.

To enroll in Fitness Following Disability or obtain information

"It's not only the physical part, it's also the social part. They get to know each other. It's something he looks forward to."

– Harriet Roberts, wife of Baxter YMCA program participant

of adaptive fitness tools provided by both the YMCA and UIndy. "This isn't a therapy session. It's a community fitness class. We ask the participants what they want to do. It's about what they want to accomplish with their fitness," Whalen said.

The wellness benefits of the Fitness Following Disability program don't end with physical fitness. Social interactions and the formation of new friendships keep multiple participants enrolling in session after session.

Ted Roberts has been participating in the class for more than four years, working to improve his fitness following a 2002 stroke. "It's not only the physical part, it's also the social part. They get to know each other.

on other Baxter adaptive programs, contact David Smith, Baxter YMCA wellness director, at (317) 865-6463 or dsmith@indymca.org. The class is free to YMCA members; the fee for nonmembers is \$25 for a 12-week session. *

Find a program in your area

To find other sports and recreational programs near you, visit the National Center on Physical Activity and Disability's website at www.ncpad.org and click on "Programs." The website provides information and links to a wide variety of sports and fitness programs throughout the state. Some of Indiana's offerings include:

- **Iron Horse Therapeutic Riding Center Inc.:** Located in Hebron, Ind., Iron Horse offers year-round hippotherapy and therapeutic riding programs. Call (219) 996-3484 or visit www.ironhorsetherapeuticrc.com.
- **Turnstone:** It is the mission of this Fort Wayne-based organization to "enhance the lives of all persons with disabilities and their families," with programs such as quad rugby and power soccer. Call (260) 483-2100 or visit www.turnstone.org.
- **Paoli Peaks:** This southern Indiana ski resort offers adaptive lessons for people with disabilities learning how to ski or snowboard. Call (812) 723-4696 or visit www.paolipeaks.com. *



Disability advocate exemplifies healthy living

Rahnee Patrick understands the importance of living a healthy lifestyle. “I’m trying to stay on this Earth as long as possible,” said Patrick, a graduate of Partners in Policymaking, the Indiana Governor’s Council for People with Disabilities’ advocacy training program.

Thirty-six-year-old Patrick, a South Bend, Ind., native and current Chicago resident, was diagnosed with psoriasis at age eight, arthritis at age 10 and depression at age 16. Patrick knows these conditions can put you at risk for other health complications, and she’s determined to avoid them by eating right and getting adequate exercise.

“I’m really concerned about my cardiovascular health. Arthritis and psoriasis, because of the inflammation they cause, can affect blood vessels. So I’m really worried about my heart and lungs being at the strength level to give me everything they can,” Patrick said. “I also have a heart murmur,

so I have to watch that too. And then there’s a higher risk of diabetes for people with psoriasis. People with multiple chronic health conditions have to watch and make sure we are taking care of what we already have.”

In 2008, after attending preparatory physical therapy sessions, Patrick enrolled in a gym. Her physical therapist helped her

An active disability rights advocate and director of independent living at Chicago’s Access Living, Patrick’s schedule is packed with activities ranging from organizing rallies to lobbying to mentoring others with disabilities. While her schedule is busy, Patrick realizes that without good health, her advocacy efforts would be limited. Therefore, she has since transitioned workouts into her home to better

“I know a lot of people who are also health conscious, even more so than me, so I look to them for ideas and advice.”

– Rahnee Patrick, disability advocate and Partners in Policymaking graduate

learn to use the facility’s machines. “According to the Americans with Disabilities Act, everybody has the right for an assistant to go with them. He came with me and demonstrated how to use the machines with wrist supports. I use supports to use the machines because my hands can’t really grip the bars,” Patrick explained.

incorporate fitness routines into her busy schedule. She now regularly utilizes a stationary bicycle, weights and a workout video.

Walking has also become an important element of Patrick’s fitness, providing both physical and mental health benefits.

“My husband and I have a dog. I take her out for walks, and that’s really motivating. It’s important for me to engage with the community. I don’t even have to talk to people; it’s just good for me to go out,” Patrick said. “And it also helps the disability rights movement because it gets people to realize that people with disabilities aren’t just living in our homes all by ourselves. We aren’t shut-ins or home-bound. We are part of the community.”

Patrick’s advice for others wishing to improve their health or fitness: recruit a support system of people who will provide encouragement and help you follow a routine.

Patrick finds regular support from her husband, Mike, particularly to help her eat healthier. Mike makes sure she eats at least half a plate of vegetables with every

dinner. And, at social gatherings, when poor eating habits often run rampant, Mike uses code words to help his wife avoid temptations. “If he notices that I’m unconsciously eating, he says a word like ‘banana.’ Having a code word can trigger you to get out of that mindless eating and be thoughtful about everything that you’re putting into your body,” Patrick explained.

By sticking to a routine, healthy activity becomes a natural part of life. For instance, even if Patrick does not feel physically able to go for a walk, she sticks to her daily routine of walking her dog by making a slight modification. “Sometimes my joints are too sore, so I use my power wheelchair and I’ll walk her in my chair. Even that is uplifting,” Patrick said.

Surrounding herself with other health-conscious people, staying abreast on fitness news, and determination are also Patrick’s keys to success. “I know a lot of people who are also health conscious, even more so than me, so I look to them for ideas and advice,” she said. Patrick cites picking up others’ habits, like cutting out salt or switching to low-calorie butter, as easy ways to live a healthier lifestyle. She also recommends subscribing to health care publications.

Patrick appreciates her state of health for what it is, yet strives to continually make improvements. “I am totally happy that I have my disabilities because I feel like it’s an important perspective that I hold. At the same time, I would just kind of like to keep it at these. That’s why I take care of myself.” *



Fight illness and improve health with regular physical activity

Obesity is a growing epidemic in the United States, affecting nearly 30 percent of Hoosiers, according to the Centers for Disease Control and Prevention (CDC). Carrying unhealthy weight brings a host of health risks, including heart disease, high blood pressure, stroke, type 2 diabetes, high cholesterol, cancer, osteoarthritis, sleep apnea and more.

The obesity rates among adults and children with disabilities are 57 and 38 percent higher, respectively, than rates among adults and children without disabilities, according to the CDC. Furthermore, individuals with existing health conditions are

- Increased cardiac (heart) and pulmonary (lung) function
- Improved ability to perform activities of daily living
- Protection against development of chronic diseases
- Decreased anxiety and depression
- Enhanced feeling of well-being
- Weight control
- Lowered cholesterol and blood pressure

Reaping the benefits of exercise

People with disabilities are more likely to be sedentary than

- Exercise doesn't have to be strenuous to provide physical and emotional benefits.
- A variety of organizations, including public agencies, health care organizations, fitness and sports clubs, recreational centers and parks departments, provide exercise opportunities that are accessible for people with disabilities.
- Enjoyable activities can offer health benefits. Consider outdoor activities, sports or other areas of interest.
- Setting goals before beginning an exercise program creates motivation.

Getting started

Before entering into any fitness program, consult with your doctor to ensure your health is in appropriate condition to engage in physical activity. Your physician can provide recommendations for the amounts and types of physical activity that are appropriate for your situation.

In addition, refer to the Physical Activity Guidelines for Americans established by the U.S. Department of Health and Human Services. The guidelines include these specific recommendations for people with disabilities:

- Try to get at least 2.5 hours of moderate-intensity or 75

Regular physical activity is one of the surest ways to ward off disease, improve overall health and ultimately enjoy a better quality of life.

more likely to develop secondary problems if they are overweight.

Regular physical activity is one of the surest ways to ward off disease, improve overall health and ultimately enjoy a better quality of life. The National Center for Physical Activity and Disability (NCPAD) identifies a multitude of exercise benefits for people with disabilities – and all individuals:

individuals without disabilities, mostly due to barriers such as physical limitations, lack of programming or knowledge on how to adapt activities, inaccessible facilities and financial constraints.

The NCPAD provides these practical tips to help people with disabilities adopt healthier, physically active lifestyles:

minutes of vigorous-intensity aerobic activity per week (or an equivalent combination of the two). A moderate activity can be walking for leisure or gardening. Vigorous activity could be playing a game of wheelchair basketball.

- If able, perform muscle-strengthening activities of moderate or high intensity that involve all major muscle groups on two or more days per week. Strengthening your muscles improves posture, balance, coordination, bone density and energy levels.

When adults with disabilities are not able to meet the above guidelines, they should engage in regular physical activity according to their abilities, based on their physicians' instructions, and should avoid being too sedentary. The recommendations mentioned above should be adapted to meet the unique needs and circumstances of each individual.

When engaging in any type of physical activity, it's important to take precautions to avoid injury. Be sure to wear the proper gear and use the correct equipment; drink plenty of water to avoid dehydration; and warm up and stretch appropriately to avoid muscle strains and other injuries.

For more information and resources, visit www.hhs.gov and click on the "prevention" tab.

Adapting exercises for people with disabilities

Physical activity comes in all shapes and sizes and can be modified for an individual's abilities and unique circumstances.

Physicians, physical therapists and personal trainers can recommend the most suitable exercises for individuals with health conditions and disabilities.

Several types of sports, such as basketball and tennis, are commonly adapted for people who use wheelchairs. There is also a variety of fitness equipment specifically for individuals with physical disabilities, such as exercise bikes that can be used while seated in a chair, arm bikes, weight machines and FES bikes, which are designed to mechanically stimulate and exercise paralyzed muscles.

The New York State Department of Health offers these additional tips for making exercise accessible for people with disabilities:

- If you're walking, riding a bicycle or engaging in wheelchair activities, look for a well-lit walkway with ample width and curb cuts.
- Look for inclusive, universally accessible exercise programs that provide the opportunity to meet other individuals, both with and without disabilities.
- If interested in joining a gym, tour the facility to identify any barriers and request necessary modifications for accessibility.
- Individuals using wheelchairs should focus physical activity on increasing their upper-body strength, which will make it easier to maneuver a manual wheelchair.

The NCPAD website offers physical activity tips for a variety of disabilities. Visit www.ncpad.org/disability.

The CDC dedicates a section of its website to health for people with disabilities. Visit www.cdc.gov/ncbddd/dh for information and resources specifically to help people with disabilities develop healthier lifestyles. *

Children and physical activity

According to the CDC, 20 percent of children ages 10 to 17 who have special health care needs are obese, compared to 15 percent of children of the same ages without special health care needs. The availability of sedentary entertainment, like video games and television, has given kids an unhealthy alternative to physical activity.

Children with disabilities benefit just as much from physical activity as their peers without disabilities. According to the American Academy of Pediatrics (AAP), children with disabilities need regular physical activity to maintain normal muscle strength, flexibility, joint structure and function. Furthermore, physical activity may slow the functional decline often associated with some disabilities.

Just as for adults, it's important to consult with a child's physician to determine the appropriate amounts and types of physical activity for the child's specific abilities and needs. Each child's overall health status, individual activity preferences, safety precautions and the availability of accessible programs and equipment must be considered. *

How to get the best care from your physician

Health care reform ushered in a renewed focus on preventive health, emphasizing the need for all of us to take a proactive role in our medical care to ensure the best treatment possible. In addition to living healthier lifestyles and getting regular medical check-ups to guard against illness, preventive health care emphasizes the need for patients to build and maintain relationships with their health care providers and make the most of their doctors' visits by preparing for appointments and asking the right questions.

Because people with disabilities typically visit their doctors more regularly than other individuals, and depend even more so on quality medical care, it is especially important for these individuals – or their caregivers – to fully participate in the physician-patient relationship. To ensure you receive the best patient experience and optimal care from your physicians, consider these important recommendations:

Find the right physician for you

If you don't have a primary care physician, work with your insurance carrier, including Medicaid and Medicare providers, to find a physician who fits your needs. You can also get recommendations from friends and family, but be sure to ask if the physician accepts your insurance.

A primary care physician, or your insurance provider, can refer you to specialists when needed.

When seeking a physician, schedule appointments with potential doctors to discuss your needs and ask questions to determine if the physician is appropriate for you. Consider asking:

- Is the doctor experienced in caring for patients with disabilities?
- Does the physician accept your health insurance?
- What are the physician's hours of operation, and can he/she or his/her staff be reached when the office is closed?
- Does the doctor have a helpline or a nurse whom you can contact with questions?

Address access issues

When searching for a physician, a primary consideration is the office's accessibility, including its facility, services and operations.

Patients with disabilities are entitled to certain accommodations by law. Medical care facilities are considered places of public accommodation and are, therefore, included in the facilities that are not allowed to discriminate against people with disabilities under the Americans with Disabilities Act (ADA).

In addition, the Rehabilitation Act prohibits discrimination by individuals receiving federal funds or financial assistance, including physicians who accept Medicare and Medicaid.

The Disability Rights Education and Defense Fund (DREDF) issued a report in 2007 outlining the top three categories of barriers to the delivery of health care for people with disabilities: financial, structural and programmatic.

Structural barriers consist of the architectural characteristics of a medical office, including parking, entrance locations, doorway and hallway widths, accessible restrooms, stairs and ramps. Programmatic barriers refer to a physician office's operational policies and procedures; the accessibility of the equipment used for medical examinations; the medical responses of doctors and nurses to patients with disabilities; and the physician's and other staff's lack of professional expertise in providing care to individuals with disabilities.

When searching for a new physician, consider your unique accessibility needs. Talk to the doctor or his/her office manager to determine if the facility, equipment and staff will be able to accommodate you. DREDF suggests considering the following:

- Does the office provide communications in an alternate format that's suitable for you?
- Does the office offer an alternate, confidential way for you to provide medical information, if the standard format isn't suitable for you?
- Will the office allow you to have additional time for your appointment, if needed?
- If you're using public transportation, will the office be flexible if you arrive late to your appointment?

The typical amount of time that a primary care physician spends with a patient during a routine visit is just shy of 16 minutes, according to a 2007 *American Medical News* article.

- If needed, does the office have available staff to help you transfer from a wheelchair to an examination table?
- Is the facility fully accessible for you, including the waiting area, examination rooms and restrooms?
- Are facilities to which you may be referred for additional care, such as laboratories, testing areas and specialists' offices, also accessible?
- Do the primary physician and his/her staff have positive attitudes toward people with disabilities?

Make the most of your doctor's visit

The typical amount of time a primary care physician spends with a patient during a routine visit is just shy of 16 minutes, according to a 2007 *American Medical News* article. To make the most of this short window,

it's important to come prepared to appointments and be an active participant in medical decisions that affect you.

The National Institute on Aging offers the following steps to get the most from doctor's appointments:

- Prepare a list of health concerns you wish to discuss.
- Bring a list of your current prescriptions, over-the-counter medications and vitamins.

- Consider bringing a family member or friend who can listen, help clarify issues and, when necessary, serve as an advocate to help get your questions answered.
- Prepare to mention changes in appetite, sleep habits, energy level, mood and emergency room visits.
- Ask your doctor if you're up-to-date on all your necessary shots and tests.
- Research and ask questions about various tests and treatments that may be warranted for your condition.
- If you feel your concerns have not been addressed, seek a second opinion. *

Helpful tips for your physician

Consider sharing these tips with your doctor to help him or her serve you and other patients with disabilities:

- Ensure the facility and services are compliant with the ADA. Physical attributes of a barrier-free facility include: adequate parking spaces close to the entrance; a clear and smooth-surface path of travel to the office entrance; a ramp to the entry doors, if there are steps; and doorways that are wide enough to accommodate patients in wheelchairs. Use the ADA checklist available at www.ada.gov/checkweb.htm to identify other possible barriers.
- Develop policies and procedures that address reasonable accommodations and proper etiquette in serving people with disabilities.
- Take time to research and understand each patient's specific disability to offer the best medical treatment and accommodations.
- Allow the patient to be an active participant in his or her treatment.
- As a reasonable accommodation, minimize wait time and allow additional time for the appointment. *



Health care policy moves forward in new direction

Affordable Care Act takes effect step by step

Health care changes resulting from the Patient Protection and Affordable Care Act, the product of health care reform, are beginning to take shape. Several of the law's provisions have gone into effect, and others will be phased in over the next few years.

The government health care website, www.healthcare.gov, provides an interactive timeline that identifies when the various provisions were, or will be, implemented. The following list highlights some of the most relevant changes for people with disabilities.

Changes that are now in effect

Insurance companies are **prevented from denying coverage to children** under age 19 due to pre-existing conditions.*

It is **illegal for insurance companies to deny payment for services** due to an error or other technical mistake on a customer's application.*

Insurance companies **cannot impose lifetime dollar limits** on essential benefits, such as hospital stays.*

Consumers can **appeal coverage determinations or claims** to their insurance companies, which will be cycled through an external review process.*

States can apply to receive federal grants to help **set up or expand consumer assistance programs.**

Young adults can now **stay covered under their parents' health plans until age 26.***

Payments to rural health care providers are increased in an effort to **attract and retain medical professionals in underserved areas.**

A new Center for Medicare and Medicaid Innovation was established to begin **testing new ways of delivering care** to patients, which is intended to improve the quality of care and reduce the rate of growth in health care costs.

Changes taking effect in 2011 and beyond

The new Community First Choice Option will allow states to **offer home- and community-based services to individuals with disabilities through Medicaid**, as opposed to institutional care in nursing homes. (Effective Oct. 1, 2011.)

Individuals who acquire disabilities will be able to **voluntarily enroll in a long-term care insurance program** – called CLASS – to receive cash benefits. (Effective Oct. 1, 2012.)

A **Health Insurance Exchange will be established** as a competitive marketplace where individuals and small businesses can purchase health coverage. (Effective Jan. 1, 2014.)

Tax credits will be available for individuals with incomes between 100 percent and 400 percent of the poverty line (considered middle income) to purchase health coverage, if they are not eligible for other affordable coverage. (Effective Jan. 1, 2014.)

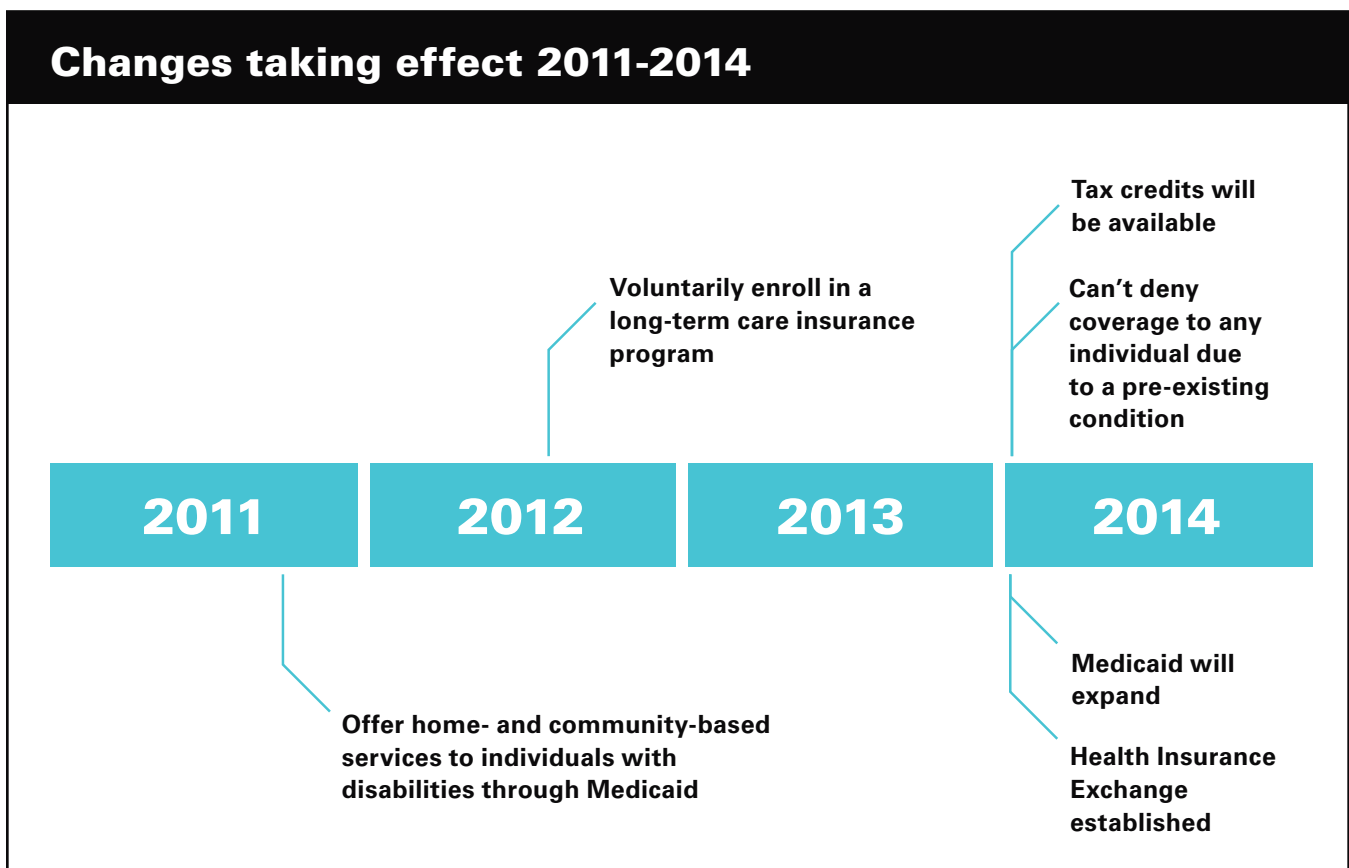
Insurance companies will be **prohibited from denying coverage to all individuals**, including children, due to pre-existing conditions. (Effective Jan. 1, 2014.)

Medicaid will expand, allowing individuals who earn less than 133 percent of the federal poverty level to be eligible. (Effective Jan. 1, 2014.)

The health care website provides a comprehensive section dedicated to explaining the new health care law as it relates to people with disabilities. Simply click on “people with disabilities” from the home page at www.healthcare.gov.

**Applies to health plans that took effect on or after Sept. 23, 2010.*

Changes taking effect 2011-2014



The Governor's Council's position on health care policy

With new legislators on Capitol Hill and in the Indiana General Assembly, health care policy continues to be a point of debate at the state and national levels. The new government make-up could mean changes to the already-passed Affordable Care Act. As health care policy evolves, the Governor's Council for People with Disabilities supports policies, legislation and practices that align with the following health care statement and beliefs:

Policy Statement

Quality, affordable, accessible health care that meets the needs and choices of people with disabilities and chronic conditions, including home- and community-based alternatives in long-term care, is an essential ingredient for participating fully in all aspects of life.

Beliefs and Conditions

The measures and rewards used for evaluating quality health care should be aligned with health care outcomes. A test of an effective health care system is how well it serves people with disabilities and chronic conditions. A quality health care system focuses on wellness. It includes a comprehensive array of services that addresses prevention, health, mental health, dental, vision, hearing, nutrition, rehabilitation and other specialty needs, delivered through a primary care, medical home model. Many people, including people with disabilities, are uninsured or underinsured.

People with disabilities often cannot access health care services and facilities that match their specific needs or are denied services to maintain their health status. Many people are forced to use costly emergency room services as their primary health care resource. People with disabilities often face discriminatory practices due to denial for coverage of pre-existing conditions; the use of confusing and complicated automated communication technologies; the complexity of application for eligibility process; denial for ongoing and specialized services; and complicated billing and explanation of benefits.

Health care providers have a lack of knowledge and expertise regarding the health care needs of people with disabilities. People with disabilities often have multiple providers and subsequently experience a lack of communication and coordination which potentially jeopardizes quality care.

Position

The Council supports legislation, policy and practices that:

- Provide everyone with accessible, affordable health care that is delivered in community-based settings.
- Ensure providers are trained to recognize the unique needs of children and adults with disabilities and to refer patients to specialty providers when needed.
- Promote the health and wellness of all people, including those with disabilities.

- Encourage consumer choice in health care.
- Implement full mental health parity.
- Ensure access and affordability of prescription medications (as well as provision of brand name drugs when medically necessary) and durable medical equipment, devices and other technologies, including repair and replacement.
- Encourage people to make healthy choices.
- Promote a healthy living environment free from pollutants and hazards.
- Expand Medicaid Waivers to eliminate waiting lists and ensure home- and community-based alternatives in long-term care.
- Support research that improves the quality of life for all people, including those with disabilities.

Terms and definitions

Medical home: An approach to providing comprehensive primary care that facilitates partnerships between individual patients, their personal physicians and, when appropriate, the patient's family.

Medicaid waiver: The source of combined federal and state funding for services available to clients who are eligible for Medicaid but choose to remain in the community.

References

Families USA, "Americans At Risk: One in Three Uninsured," (2009). *

Health + wellness resources

YMCA

www.ymca.net
(800) 872-9622 (voice)

Visit the national YMCA website to discover tips for healthy and active lifestyles, as well as links to your local YMCA.

The National Center on Physical Activity and Disability (NCPAD)

www.ncpad.org
(800) 900-8086 (voice)

This organization offers guidelines to consider before starting an exercise program and fact sheets on a variety of recreational and competitive sports for people with disabilities.

INShape Indiana

www.in.gov/inshape/index.htm
(800) 433-0746 (voice)

Operated through the Indiana Governor's Council for Physical Fitness and Sports, this program provides healthy living suggestions for physical activity and nutrition.

National Center on Accessibility (NCA)

www.ncaonline.org
(812) 856-4422 (voice) or
(812) 856-4421 (TTY)

Based out of Indiana University, NCA works to promote access and inclusion for people with disabilities in parks, recreational facilities and tourist attractions.

World T.E.A.M. Sports

www.worldteamsports.org/home
(855) 987-8326 (voice)

This non-profit brings athletes with and without disabilities together to form fully inclusive teams to compete in athletic events such as Sea to Shining Sea, a bicycle race from San Francisco to Virginia Beach.

The Adaptive Adventure Sports Coalition (TAASC)

www.taasc.org
(614) 940-1295 (voice)

This Columbus, Ohio-based organization offers people with disabilities opportunities to participate in adventure sports such as kayaking, water/snow skiing, ice skating and sailing.

National Sports Center for the Disabled (NSCD)

www.nscd.org
Denver, Colo., office
(303) 293-5711 (voice)
Kansas City, Mo., office
(816) 513-7571 (voice)

From snowboarding to horseback riding to rock climbing, NSCD offers both summer and winter fitness activities.

BlazeSports America

www.blazesports.org
(770) 850-8199 (voice)

A direct legacy of the 1996 Summer Paralympic Games in Atlanta, BlazeSports America is a non-profit that offers information on how to create and sustain sport and recreation programs for people with physical disabilities.

Midwestern Amputee Golf Association

www.mwaga.org
(847) 291-9208 (voice)

Learn how golf can be used as a vehicle in physical and mental rehabilitation processes.

Indiana Medicaid

www.indianamedicaid.com
(317) 713-9627 (voice) or
(800) 457-4584 (voice)

Find answers to Medicaid questions and learn more about specific programs.

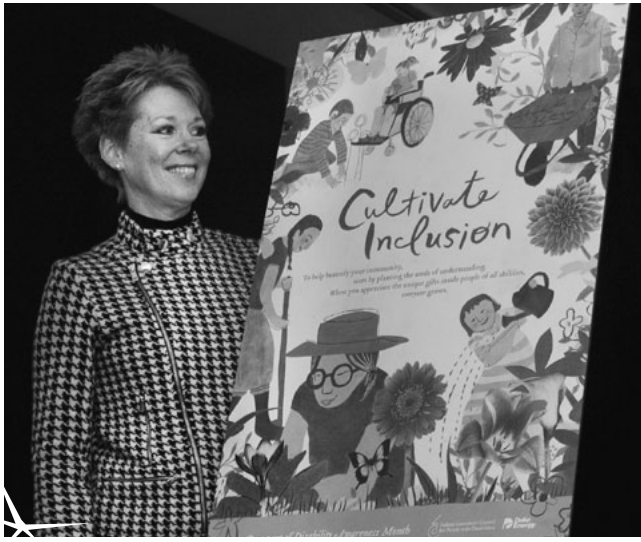
American Heart Association

www.heart.org
(800) 242-8721 (voice)

From exercises to recipes, learn how to lead a heart-healthy life.

Indiana Conference for People with Disabilities inspires action

The 2010 Conference for People with Disabilities, held Dec. 6 and 7 in Indianapolis, took more than 450 attendees on an inspirational two-day journey filled with motivational speakers, interactive workshops and plenty of networking. Themed "Going Places," the Conference ignited people with disabilities' self-advocacy spirit, instilling optimism and encouraging action.



Julie Griffith of Duke Energy received a framed Disability Awareness Month poster to recognize the company for sponsoring the 2011 campaign.



Conference attendees explored more than 20 exhibitor booths and had the chance to speak with representatives from various organizations supporting people with disabilities.



During the Conference, attendees could participate in the Indiana Disability Poll to help shape the state's Disability Plan for 2012-2016.

Conference opens with disability policy outlook

The 2010 Indiana Conference for People with Disabilities opened in Indianapolis on Dec. 6 with a journey through the past, present and future battles for people with disabilities' civil rights. Keynote speaker Bobby Silverstein, former staff director and chief counsel for the Senate Sub-committee on Disability Policy, recalled the historic mistreatment of people with disabilities that ultimately led to the Americans with Disabilities Act (ADA) and other laws prohibiting discrimination.

"It (mistreatment of people with disabilities) dates back to the philosophers – Socrates, Plato, Aristotle – who laid the foundation for Western principles and values," said Silverstein, known for his instrumental role in the passage of the ADA, among other laws.

Although these notable philosophers are credited for many valuable insights, their perceptions of people with disabilities were misguided. Silverstein quoted Aristotle, who recommended a law that would have prohibited "crippled children" from being reared, and Plato, who believed "unhealthy" individuals were unfit for the community.

Laws such as the ADA and the Individuals with Disabilities Education Act (IDEA) came about to protect individuals with disabilities from these prejudicial barriers, but Silverstein stressed that society must truly understand

the meaning of these laws if they are to be fully effective. He outlined a number of underlying messages embedded in these laws that are intended to cultivate positive behaviors toward people with disabilities:

- Disability is a natural and normal part of life that doesn't in any way diminish a person's right to participate fully in society.
- Every person should be treated as an individual, casting labels and stereotypes aside.
- People with disabilities should be given effective and meaningful opportunities to inclusively participate in society.
- Individuals with disabilities must be actively involved in policymaking by advocating for their rights.
- People with disabilities need access to proper education and job training to have the opportunity to be economically self-sufficient.

"We really mean it," Silverstein said as his last message. "These are not just principles and goals. We expect implementation and enforcement."

"Is our work over?" Silverstein asked the audience. A resounding "no!" came from the crowd.

Silverstein stressed the need for progress in many areas.



Bobby Silverstein, known for his behind-the-scenes work to help pass the ADA, opened the conference with an uplifting presentation.

Employment opportunities must be enhanced by making competitive, integrated employment a priority. The education system must strike a balance that sets high academic expectations, but that doesn't deter school systems from having students with disabilities in their classrooms out of fear of low academic and standardized testing scores.

"We have a lot of work ahead in a time of fiscal crisis," Silverstein said. "Is the disability community up to the task?"

Without hesitation, the audience shouted "YES!" *



Several Conference attendees participated in an interactive drum circle workshop – a fun, energy-boosting session with lots of music and laughter!



Suellen Jackson-Boner (left), executive director of the Governor’s Council, presented a Community Spirit Award to Linda Muckway of Muncie, Ind., for her exemplary advocacy efforts as a person with a disability.



Steve Tilden (left), board chair for the Governor’s Council, presented a Community Spirit Award to Mary Jo Paladino of Granger, Ind., for her outstanding advocacy work as a parent of a child with a disability.



The first day of the Conference ended with a cruise-ship themed reception where attendees socialized and danced into the night.



Conference attendees were invited to share their stories on camera at the Story Tent. The videos will be available on YouTube in the near future.



Johnnie Tuitel – a renowned speaker, author, entrepreneur and visionary – inspired the audience with his keynote presentation surrounding his motto: “Handicapitalism.”



Disability Awareness Work Group (D.A.W.G.), a coalition of various organizations in Terre Haute, Ind., received a Community Spirit Award for conducting an exceptional Disability Awareness Month campaign in March 2010.

Conference closes with a call to advocacy

Following several inspirational keynote sessions and workshops, and many opportunities for networking with peers, the Indiana Conference for People with Disabilities concluded with a panel discussion that encouraged attendees to help shape Indiana's future legislative landscape through collaboration and advocacy.

Titled "Construction Ahead: State Legislative Panel," the session featured panelists John Cardwell, director of The Generations Project; Kim Dodson, associate executive director of The Arc of Indiana; Nancy Griffin, disability advocate and consultant; and Steve McCaffrey, president and CEO of Mental Health America of Indiana.

The overarching theme addressed by the panelists was the 2011 legislative budgetary session. "This budget session is an issue because it will determine the future of our services," McCaffrey said. "It is going to be difficult, but we can be successful with our advocacy efforts."

Among the potentially affected services are the Community and Home Options to Institutional Care for the Elderly and Disabled (CHOICE) Program and Medicaid waivers. "Right now there are about 8,500 to 9,000 Hoosiers waiting for the CHOICE program or a Medicaid waiver. Those numbers are way too high," Cardwell expressed. "People need

access to these programs because they keep individuals out of institutions. They keep people free and engaged in the community."

Indiana offers approximately 30 optional services through Medicaid, such as prescription drug coverage, that could also be affected. "Optional services are at risk during a tough budget time,

"Right now there are about 8,500 to 9,000 Hoosiers waiting for the CHOICE program or a Medicaid waiver. Those numbers are way too high."

– John Cardwell, director of The Generations Project

and we need to make it known that those are essential services," Griffin explained.

According to Dodson, education, health care and social issues will be hot topics for the state's general assembly throughout 2011. Priorities for disability advocacy will include legislation preventing seclusion and restraint, as well as bullying. Dodson said The Arc hopes to secure the passage of smoke-free air legislation, as well as legislation on increased education for suicide prevention.

The panelists remained optimistic of the coming year's assembly. "There are 30 new members in the Indiana General Assembly, which means that it's a great opportunity to lay the foundation for relationships," Dodson said.

Griffin agreed, commenting, "We can educate the legislators. They aren't against us, they just don't know us. These are not unapproachable people. They are our neighbors, our community members, and we need to share our stories with them."

Cardwell even suggested advocates "adopt" a member of the House

and the Senate and persistently ask for the passage of disability rights legislation. "If you are told 'no,' ignore them. Push forward in your advocacy, and remember that 'yes' is the right answer. If you persist with your message, legislators will begin to discuss it with their colleagues," Cardwell said.

Find your local legislators at www.in.gov/legislative/legislators. To stay up-to-date about bills and resolutions being discussed during the legislative session, visit www.in.gov/apps/lisa/session/billwatch/billinfo. *

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