

# Disability Issues

*Providing people with disabilities, their families, friends, and advocates with relevant information that enables individuals to improve the quality of their life, health and employability options.*

Volume 36 • No. 1

Winter 2016

## Uses and Benefits of Mind – Body Practices

By Mary Grimley-Mason

**"We now know that roughly sixty to ninety percent of doctor visits are for conditions related to stress."**

This statistic, according to the Benson/Henry Institute for Mind-Body Medicine, is a massive public health issue. The Institute at Massachusetts General Hospital (MGH) was founded to address this problem and make Mind-Body Medicine an integral aspect of health care.

Dr. Henry Benson, The founder of the Institute, an early enthusiast of Eastern alternative medical practices such as meditation, established the scientific basis for the mind-body connection in the late 1960s. He and his colleagues at MGH conducted studies using meditation and found that metabolism, rate of breathing, heart rate, and brain activity were reduced. Benson called this outcome "the relaxation response." Other medical centers and doctors have continued or further developed this practice, notably the Center for Mindfulness Medicine, Healthcare and Society at the University of Massachusetts Medical School founded by Dr. Jon Kabat-Zin.

My personal experience with this Mind-Body practice comes from an eight-week course given at my retirement community this fall.

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## AccessSportsAmerica

By Mary Jane Fietze

**ASA's mission: To inspire higher function and fitness for children and adults of all disabilities through high-challenge sports and training.**



**Are you looking for a place to work out...** but are intimidated by the bulked-up body-builders that look like Arnold Schwarzenegger at your gym? Is the equipment simply not made for someone with your disability? Have you employed a personal trainer whom, frankly, did not understand your disability? Does this sound like a TV ad that you might hear after all your New Year's Resolutions are broken? Well, expect the unexpected.

AccessSportsAmerica (ASA) offers personal training sessions year-round for people with a variety of disabilities every Monday and Friday, 9am-2pm at the YMCA in Oak Square in Brighton, MA. It is easily accessible by The T, The Ride, or a quick hop from either the Mass. Pike or downtown Boston. There is financial aid available, but their goal is to get you to work out as often as possible; thus the fee is negotiable if you commit to two sessions a week. Just be prepared to sweat and smile.

Nate Berry, ASA Program Director, shared with me, "We have discussed getting our own gym, but then you might not be working out alongside someone that is different than you, and the social aspect of working out is huge!" Trainees are integrated into a normal gym atmosphere where caring, compassionate Trainers challenge them. The ASA's full-time trainers are taught to tailor your work out to your specific skill level. The only difference from a normal YMCA experience is that many of the machines are adapted to accommodate each person's specific disability. A typical work out involves cardio, core work, stretching, and gait training.



Ross Lilley founded ASA in 1995. He is an innovator in creating adaptive equipment for many sports, which are custom fit to an individual's disability. They have developed an adaptive device that works with any treadmill, which simulates gait training and is designed for someone who thinks they couldn't possibly step on a treadmill.

*Continued on page 2*

## **AccessSportsAmerica** - Continued from page 1

Rey Vazquez is a 34-year-old male who suffered a stroke 4 years ago. He describes his ASA experience, "Until I met the crew from AccessSportAmerica, I thought that I would never play sports again. They changed my life. I now play soccer and tennis, and I have learned to canoe, ski, and windsurf. Going to the YMCA and working out with ASA has improved my balance, core, and stamina. They make working out fun, but I definitely feel it after a workout. They have helped me physically and mentally; because, before ASA, I suffered from depression. ASA is a great organization that helps people like me do things that I thought I couldn't do anymore."

Nate said, "It is rewarding to see people do things which they never thought were possible even before their disease, illness, or accident."

In the Spring of 2011, I briefly trained with ASA at their outdoor facility in Charlestown where they run a program in conjunction with Spaulding. The outdoor sports consist of cycling, canoeing, windsurfing, and many more. Each activity is adapted to one's personal capabilities. My goal was to complete 5 miles on my hand cycle in *Run to Home Base*, an event to raise money for **Home Base** - a program established by the Red Sox and Mass General, which raises money for Veterans with Post Traumatic Stress Disorder and Traumatic Brain Injuries. ASA was supportive, yet they challenged me to push myself.

I never thought I would be able to finish the 5-mile race. The first time I raced, I finished in 50 minutes without shifting gears. I wanted to race again the following year and improve my time, so in the snowy winter of 2013, I trained with ASA weekly at the YMCA in Brighton. They helped me with core training and conditioning in preparation for the April road race. This time I completed the 5-mile race on my adaptive hand cycle in 35 minutes, using all 28 gears! I have Multiple Sclerosis and am mobility challenged, but after training with ASA, I truly believe that nothing is out of bounds and I now consider myself an athlete. They have instilled confidence in my physical abilities and genuinely have changed my life.

For a life-changing experience, sign up now for personal training with AccessSportsAmerica at the YMCA in Brighton. They also offer conditioning and tennis at Harvard University's indoor courts on Wednesdays, October-May.

AccessSportsAmerica's goal is to "Train for Life". For more information, visit [www.accessportamerica.org/participate](http://www.accessportamerica.org/participate)

*Mary Jane Fietze Has been living with Multiple Sclerosis for 24 years. She writes for The Burlington Union about disability topics and has been on the Burlington Disability Access Commission (BDAC) for 13 years. Mary Jane has won several awards in hand-cycling and enjoys demonstrating her ability to kids as part of BDAC's "differently-abled talks" to schools.*

## **Uses and Benefits of Mind-Body Practices** - Continued from page 1

A facilitator ran the weekly sessions from the Mind-Body Institute at MGH and took us through methods to elicit the relaxation response. She provided three tapes we could use ourselves and facilitated discussions about our responses to our daily practice of meditation.

I later interviewed a number of people in the sessions and talked to several others about their assessment of the course. I found that many of the participants had previously done some form of regular meditation but wished to refresh their techniques or learn new ones.

Charlie was part of seven people with Parkinson's disease who signed up for the course. He had actually consulted Dr. Benson in the past and has practiced meditation for many years. He finds the techniques effective and says that he can lower his blood pressure while waiting anxiously in a doctor's office, but he continued, "You have to believe in it. 'Mindfulness' or living in the moment is particularly useful with Parkinson's because it addresses the anxiety and unpredictability of the disease." He felt the course was useful and successful, but he guessed that of the sixty people attending the sessions, only about ten percent would keep up the practices.

Jerry, another member of the Parkinson's group, said the course was like "being acquainted with an old friend." He found it generally helpful to foster relaxation and to relieve pressure. Most importantly, he said that the Parkinson's group who took

the course agreed to meet after the regular Parkinson's Support Group meeting here to be supportive of each other. This, he said, is important because "you can't do it alone."

Other course members mentioned different benefits from the sessions. Sylvia, who knew of Benson's work in the 70s, found that putting a tape on her iPhone was helpful if she woke up at night and couldn't sleep. Others spoke of using the meditation practice in frustrating traffic jams or while waiting on hold on the telephone. Some used the meditation techniques when taking daily walks or on longer walks on the beach or elsewhere.

A common thread that ran through my conversations with participants of the course was the importance of trying to make meditation part of your life. Just as any successful form of exercise becomes integral to your life, "mindfulness" meditation is most beneficial when it becomes part of your daily routine.

### Additional References:

Herbert Benson, *The Relaxation Response*. 1975

Jon Kabat-Zin, *Full Catastrophe Living: the wisdom of your body and mind to face stress, pain and illness*. 1991

*Mary G. Mason is a PhD Professor of English emerita, Resident Scholar, Brandeis University's Women's Studies Research Center, and author of; "Life Prints: A Memoir of Healing and Discovery", "Working Against Odds: Stories of Disabled Women's Work Lives", and "Taking Care: Lessons from Mothers with Disabilities".*

Disability Issues is a publication of Spaulding Rehabilitation Network, a member of Partners HealthCare. The Spaulding Rehabilitation Network includes Spaulding Rehabilitation Hospital. Its main campus located in Boston, as well as Spaulding Rehabilitation Hospital Cape Cod, two long-term care facilities Spaulding Hospital Cambridge and Spaulding Hospital North Shore and two skilled nursing facilities, as well as twenty-three outpatient sites throughout Eastern Massachusetts. Spaulding is a teaching hospital of Harvard Medical School and the official rehabilitation hospital of the New England Patriots. Spaulding is the only rehabilitation hospital in New England continually ranked since 1995 by *U.S. News and World Report* in its Best Hospitals survey with a #6 ranking in 2013. For more information, visit [www.spauldingnetwork.org](http://www.spauldingnetwork.org).

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## From the Editor



Dear Readers,

During the cold days of winter, I often love to cuddle up on my sofa with a warm blanket and a cup of hot chocolate to watch a good movie. Sometimes, I even light a few candles to enhance the cozy ambiance.

Winter is also a time when I reflect on opening myself up to new possibilities that nurture and support holistic wellness of mind, body and spirit. I embrace this season of stillness by becoming more attuned to my inner voice and staying open to new possibilities. I pay attention to whispers that lead me to things I need to or want to do. The clues are often right in front of me and by slowing down I am able to notice them. In this quiet space, I may find a way to improve a skill, revive a forgotten passion, create beauty, deepen a relationship, or heal a broken place.

Part of seizing these opportunities is to make room for them by letting go of old habits and beliefs. Making space gives an opportunity for the unexpected to walk in the door. Spaces can be made on my calendar or by clearing away some clutter, but more important are the spaces I make in my expectations, or in the way I see myself, or in the way I see the world. To receive the next great thing in my life, there has to be a place for it to enter, take root and grow.

In this issue, we offer some possibilities to stimulate your thinking about something new you may want to engage in. In this season of stillness, I encourage you to connect with yourself and your passions in a deeper way. You never know what great adventure may be just around the corner waiting to be discovered.

Marianne DiBlasi, Editor



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# Let's Dance!

by Sandy Alissa Novack

she is doing aerobics, strengthening exercises, and stretching. She has had no back or other pain issue because dancing has made her flexible and strong.

There are a couple of myths about this form of dance. Many people think men do not belly dance, but Gypsy encourages readers to type in "male belly dancing" on YouTube to see a lot of men performing. Some potential dancers are concerned they do not have a partner with whom to dance, but you do not need a partner. Also, Gypsy says belly dancing used to get a bad reputation because people thought dancers were strippers, which they are not. Indeed, they are dressed more like gypsies than strippers. Another common question is, is Gypsy her given name? No, but she used it for Citizens Band (CB) radio

and continued using the name because it's also a nice name for a Belly Dancer, then it stuck.

Gypsy says more people could do belly dancing for exercise and fun than they think they can. For example, when her dance troupe is performing at a nursing home, residents in wheelchairs can roll their shoulders while people with walkers shimmy. Gypsy cites the joy that people experience when they see that, despite their disabilities, they can still move to music.

For more information on the Gypsy Moon Dance Company, and the adult performers aged 61 to 82 years old in the part of the Company called the Silver Moon Gypsies, go to [www.silvermoongypsies.weebly.com](http://www.silvermoongypsies.weebly.com), or contact Gypsy directly at [gypsystoys@aol.com](mailto:gypsystoys@aol.com) or call 508-393-9371.

After giving birth to her third child, Gypsy Phillips took her first belly dancing class. She found she could explain directions to her classmates better than her teacher, who relied only on showing the class how to belly dance. She has been teaching belly dancing ever since, for 42 consecutive years. She likes that the movements target every part of the body and she likes the music. She likes that simultaneously

## InfoBriefs InfoBriefs InfoBriefs InfoBriefs InfoBriefs InfoBriefs

### "Focus" on Vision Impairment & Blindness Conference – 11th Annual

#### Meeting the Needs of Individuals with Intellectual Disability & Vision Loss

March 9, 2016 • 8:00 am - 3:30 pm

Four Points by Sheraton, Norwood, MA

Keynote Speaker: Randy Pierce, President, 2020 Vision Quest

Keynote Topic: "Reaching Our Peak Potential"

#### Registration Information:

\*\* Early Registration Fee postmarked by January 31, 2016: \$50.00

Registration Fee postmarked after January 31, 2016: \$60.00

Registration needed by February 26, 2016 to attend conference.

Registration Brochure and Form, including CEU information, will be downloadable from "Training and Events" section of DDS website:

[www.mass.gov/dds/visionloss](http://www.mass.gov/dds/visionloss)

and from the "Perkins Professional Development Calendar" on the Perkins website: [www.perkinselearning.org/events-monthly](http://www.perkinselearning.org/events-monthly)

For additional information, including sponsorship, vendor or advertisement opportunities, please contact: Lisa DiBonaventura at [Lisa.DiBonaventura@state.ma.us](mailto:Lisa.DiBonaventura@state.ma.us) or 508-384-5539

### The RespectAbility Report Focuses on 2016 Elections

As the 2016 presidential campaign season gains speed, **RespectAbility** is reaching out to all of the campaigns to highlight the importance for all candidates to speak directly to voters with disabilities and their families by offering specific plans for a better future.

RespectAbility introduces its newest project – *The RespectAbility Report* – a nonpartisan political commentary on the 2016 U.S. elections with a focus on disability issues. Launched in June 2015, *The RespectAbility Report* is nonpartisan and neither rates nor endorses candidates. Expect to read fact-based updates and analysis from their staff based around the entire country. Staff writers meet with the presidential candidates and report their proposals on disability issues. In addition staff writers report from the ground on candidate forums and debates.

Other features will look at the candidates' websites to answer these questions and more: Do the candidates' websites have plans for helping people with disabilities obtain jobs? Are the sites accessible, and can you use a screen reader? Look for answer to all these, and more, on The RespectAbility Report at [www.respectabilityusa.com](http://www.respectabilityusa.com).

# Belly Dancing with Multiple Sclerosis

by Sandy Alissa Novack

Anna Connors was diagnosed with Multiple Sclerosis (MS) in 2006. It affects her walking and balance, which can make dancing tricky, she says. For the past six years, she has been learning belly dancing and performing with the Silver Moon Gypsies at local senior centers and other venues.

**Sandy Alissa Novack (SN):** Do you notice any change in your mobility function and in the quality of life that is attributed to dance?

**Anna Connors (AC):** Absolutely! The fun quotient! Just the pure joy of dance is incredible. Generally, belly dancing's slower fluid motion is much more suitable for my condition.

**SN:** What is your philosophy about exercise and movement?

**AC:** Gypsy and I say the same thing, Use it or lose it, and keep moving! As far as dancing, or anything else I do since being diagnosed with MS, my philosophy is to be flexible – not only body-wise but also on how I approach doing something. I may not be able to do something the way I used to, so try to adapt. There is always another way to take on a task, so I am creative. Gypsy always allows me to adapt moves in our dances. One of the dancers in our performing troupe is 82 years old. She can't do fast spins and quick steps either, so we kind of pair up together and adapt those steps to work for us. It really comes together and adds some visual interest. We can ALL adapt.

**SN:** Is there a particular aspect of belly dancing that is your favorite?

**AC:** I like that it is very expressive. It is very fluid, like a wave going up and down, very flowing. I like the way my hands and arms move slowly. I like the facial movements and the way I carry myself while dancing. The dance takes me over. I FEEL the movement and I move to it.

**SN:** For readers with MS or other disabilities, what would you like them to take away from reading this interview?

**AC:** When I dance, I do not feel my MS pain. I walk in with a cane, but then I adapt the belly dance. I encourage others who try to dance to adapt it to their needs in consultation with their teacher, such as whether a person can spin or not and how fast they can spin.

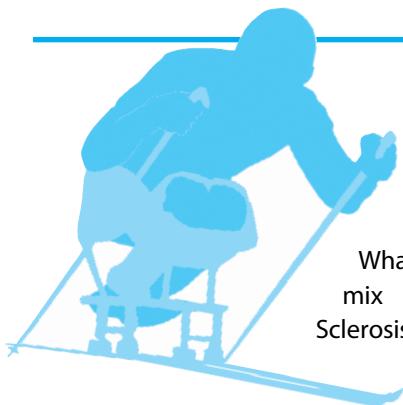
**SN:** You have a performance coming up?

**AC:** The Gypsy Moon Dance Company has two major shows a year. Saturday, January 23, 2016 in Shrewsbury will be our next one. Under my stage name of "Annika" I will have my own solo. I dedicate all my performances to people with disabilities and to rejoice in all that we CAN do.

**"Gypsy Soul",** the dance celebration of different styles of dance from traditional Middle Eastern to Modern interpretations of dance, will be held on January 23 at Maironis Park, 52 S. Quinsigamond Ave., Shrewsbury, MA 01545. Doors open at 7:00 p.m., show is from 7:30-9:00 p.m. Cost: \$7 at the door, \$5 advance sale. Reserve discount tickets by calling Gypsy at (508) 393 9371.

*Sandy Alissa Novack, MBA, MSW, LICSW, ACSW, CSW-G, is a social worker who is on the editorial board of "Disability Issues" and is on the Beth Israel Deaconess Medical Center Universal Access Advisory Council.*





## MS Cure Celebrates the 2nd Annual MS Adaptive Ski Day

By Maggie Harling and Anna Connors

What do you get when you mix individuals with Multiple Sclerosis (MS) with a remarkable group of dedicated volunteers and a whole lot of snow? You get an

MS Adaptive Ski Day of joy and camaraderie for all!

This past January the Annual MS Adaptive Ski Day took place at Sunday River Ski Resort in Newry, Maine. Sunday River is one of multiple locations for Maine Adaptive Sports & Recreation, which is the largest year-round adaptive recreation program in the state of Maine for adults and children with physical disabilities. Maine Adaptive Sports provides over 3500 lessons winter and summer, free of charge, thanks to the generous support of individuals, businesses, corporations and foundations that sustain our program every year.

The MS Cure Foundation teamed with Maine Adaptive Sports & Recreation to host this wonderful day of skiing. People with MS, their family, and caregivers came from all areas of New England to take part in this event. There were a total of seven MS participants, including myself, and my very good friend Maggie. We expected to be wrapped in bubble wrap and launched down a bunny slope. The reality of our experience was quite different.

The phenomenal staff members at Maine Adaptive Sports were warm and welcoming. They took care of all the MS skiers by outfitting each person with just the right type of adaptive ski equipment they needed. The adaptations included; using regular equipment with only the addition of an instructor, using a walker style piece of equipment with skis attached to the bottom, or a monoski which allows a person who has little or no use of their legs to ski sitting down. Each skier was paired with an instructor.

I was given a pair of ski boots, skis, and a walker with skis at the bottom instead of wheels. My instructors, both named Joe, took me out on the bunny slope with a tie around my waist. Very clumsily at first, I slowly began to remember how to ski and my muscle memory came back. The Joe's were delighted! They took me higher up the mountain. On the ski lift, I was safely wedged tightly between them. I finally got to ski down the mountain with the cold air in my face! I swear I could smell the snow!

The day was wonderful! All the participants' eyes were lit up with the pure joy of trying something they never imagined themselves able to do. Participants were full of appreciation for their volunteer instructors who go through extensive training to ensure safety for all. The volunteers had a lot of fun watching their students learn,

taking to the slopes with ease and confidence. These volunteers get a free one-year pass to the mountain when they volunteer one day per week. It's a win-win situation.

Maggie's face lit up when she told me all about her experiences that day. I could tell that she enjoyed herself to another level. She said she couldn't wait until next year to do it again!

What was most evident was my friends' unabashed joy of doing something new, going beyond her comfort zone and broadening her horizons.

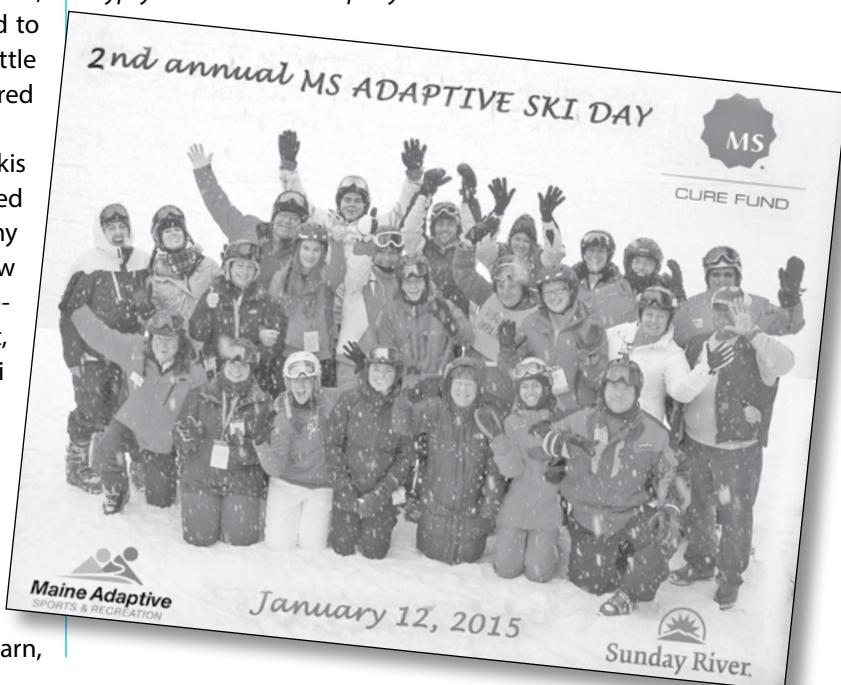
For many people living with MS, the day of diagnosis begins a steady decline in the things they can or "think" they can't do. Much of this is self-preservation. People living with MS often want to protect what abilities they do have, so they restrict themselves from anything that might put them at risk.

The MS Cure Fund invites all to this fabulous event free of charge. All meals, equipment and instruction are included. All you have to bring is a good attitude and the willingness to have fun! Maggie and I are very grateful to the MS Cure for giving us the opportunity to spend a day on the ski slopes. They are a great group that emphasizes living a quality life, not on drugs.

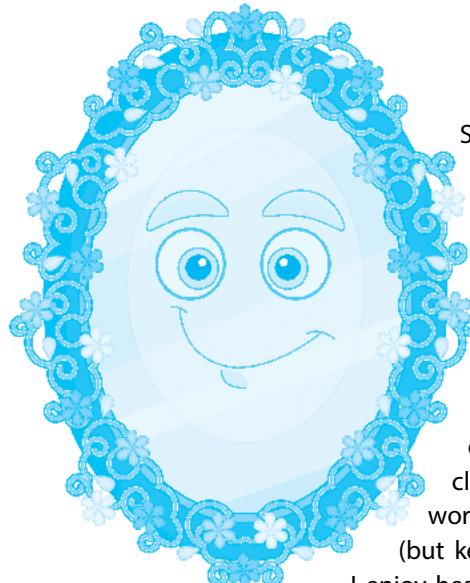
To find out more about the MS Cure Fund, visit [www.mscurfund.org](http://www.mscurfund.org) or call 617-375-9900.

To learn more about Maine Adaptive Sports and Recreation, visit [www.maineadaptive.org](http://www.maineadaptive.org) or call 207-824-2440.

*Maggie Harling and Anna Connors both live with Multiple Sclerosis. Anna is an enthusiastic member of the Silver Moon Gypsies at the Gypsy Moon Dance Company.*



# Love and Intimacy Corner



## Smile When You See Yourself Naked in the Mirror

by Ms. Love

As usual, Good Vibrations' offer practical suggestions on ways to confront negativity and shaming:

- ♥ When possible, speak up when you do not like the negative statements people are making.
- ♥ Become a critical viewer of social and media messages. Be aware of what advertisers want you to believe because they are often trying to sell something that will "fix" you.
- ♥ Learn to accept all bodies. All of us are unique and special. Beauty is not defined the same universally.
- ♥ Connect with your body. Focus on what your body CAN actually do. Do activities and make changes that make you feel good. Treat yourself to a different hairstyle, buy yourself that CD you have wanted and sing along, or learn to speak a new language.
- ♥ Surround yourself with positivity. Spend time with people who care about you. Compliment others on their quality of character, passions, and talents.
- ♥ Find "your people" so you are not alone. If you have chronic pain day in and day out, reach out to others in chronic pain and you will be amongst people who understand.

As if this wasn't enough food for thought, Adri and Natasha also handed out a two-page resource handout entitled, *Where to Find More Info For Body Lovin' Livin'*. Get yourself to Good Vibrations in Brookline, MA and ask for a copy of the full resource list from the "Does This Culture of Systematic Shaming Make Me Look Fat?" workshop. I want you all to smile with confidence when you see yourself naked in the mirror.

To get you started, check out the following two resources that are listed in the workshop handout:

- 1) The Boston-based, Pleasure Pie ([www.pleasurepie.org](http://www.pleasurepie.org)) which focuses on body and sex positivity.
- 2) For those of us who never saw ourselves reflected in our Barbie dolls and GI Joe action figures, visit the body image website, Adios Barbie ([www.adiosbarbie.com](http://www.adiosbarbie.com)). They have a special section on disabilities.

Good Vibrations is at 308-A Harvard Street in Brookline, MA. Their website is [www.goodvibes.com](http://www.goodvibes.com), and their phone number is 617-487-4990.

*The Love and Intimacy Corner welcomes questions and requests for topic areas from readers. Please send all comments, questions and suggestions to Ms. Love at [DILoveandIntimacy@gmail.com](mailto:DILoveandIntimacy@gmail.com). Questions chosen to be featured in the Ms. Love column will appear under a pseudonym to protect privacy and may be edited.*

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## InfoBriefs InfoBriefs InfoBriefs InfoBriefs InfoBriefs InfoBriefs

### Mind-Body and Adaptive Yoga DVD's

**Beyond Disability, A Yoga Practice with Matthew Sanford** illustrates the wisdom of Matthew Sanford's teaching in this full-length seated yoga practice for people of all abilities. Practice along with Matthew and his students as they guide the viewer through chapters introducing seated centering, grounding, balance, rhythm and balanced relaxation, allowing viewers to participate in one section at a time or enjoy the practice in its entirety. This DVD includes optional subtitles for those with hearing impairment. Cost: \$24.95 + shipping. Available for purchase at Amazon.com.

**Transforming Disability: A Mind-Body Approach** provides an introduction to a mind-body practice for the person living with a disability. A 13-minute inspirational video illustrates how a mind-body practice can transform the experience of living with a disability. Three audio imagery exercises and a booklet illustrating 5 exercises provide a starting point for developing a mind-body practice. Cost: \$12.99 + shipping. Available for purchase at Amazon.com.

For more information, visit [www.mindbodysolutions.org](http://www.mindbodysolutions.org)

### Health and Fitness Centers

**Peoplefit** in Woburn MA, is an award winning Health and Fitness Center, owned and operated by physical therapists. They provide a place where people of all abilities, women of all ages and men over 40 can come together and get healthy in a comfortable, non-intimidating atmosphere with constant supervision, assistance and advice under the care and guidance of licensed physical therapists. Their highly skilled professionals will create an individualized program designed to meet your specific needs and goals. A lot of support is given to members as they embrace the value of regular exercise to improve their quality of life. For more information, visit [www.peoplefit.net](http://www.peoplefit.net) or call 781-932-9332.

**Total Rehab & Fitness** in Waltham MA is a freestanding not-for-profit organization that helps people with multiple sclerosis (MS) manage their chronic illness. Their unique program includes a complete spectrum of services at one location that addresses your physical, emotion, cognitive, financial and social needs. They offer a holistic approach to help you improve your current physical and/or mental condition(s). Their services are limited to individuals living with MS. For more information, visit [www.totalrehabandfitness.com](http://www.totalrehabandfitness.com) or call 781-895-9500.