

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.

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Spring 2017

New Resource Explains Strategies and Benefits of Exercising After Burn Injury

By Tim Sullivan

A free online resource to educate the public about exercising after burn injury is now available on the Model Systems Knowledge Translation Center (MSKTC). *The Exercise After Burn Injury* hot topic module is a suite of free resources — videos, a factsheet and a narrated slideshow — that explains how exercise can enhance recovery and quality of life for people who have experienced a burn injury.

“Many people who experience a burn injury aren’t sure how to get back into an exercise routine,” said Cindy Cai, Ph.D., co-project director of the MSKTC and principal researcher with American Institutes for Research. “This suite of resources offers practical tips that can help burn survivors take the first step to getting back to physical activity.”

The main 18-minute video features three burn survivors who share the profound experience of beginning an exercise routine after burn injury. It also includes the perspectives of health care professionals at the Boston-Harvard Burn Injury Model System (BHBIMS) center, who explain the importance of and

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Go GRIT

by Mary Jane Fietze

What has three wheels, two removable arms, and improves the active lifestyle of the mobility challenged? If you guessed a broken tricycle, you would be wrong.

The correct answer is: The GRIT Freedom Chair, a new multi-use/outdoor wheelchair that helps the disabled “move beyond the pavement,” by enabling them to traverse terrain that standard wheelchairs would not dare to go.

It was first conceived by a team of students at MIT for a course in wheelchair design, who went on to found Global Research Innovation and Technology (GRIT).

GRIT was formed in 2012 by Tish Scolnik, CEO; Mario Bollini, Chief Technology Officer; and Ben Judge, Product Development. They now have five full-time employees. The team studied Biomechanics and consulted with Occupational Therapists, Physical Therapists, and wheelchair users around the world. After many prototypes the **Freedom Chair** was born.



GRIT describes the Freedom Chair as a “mountain bike for your arms.” The Go GRIT website boasts accolades from *The Boston Globe*, *Boston Business Journal*, *Time Picayune*, *Forbes*, and *Men’s Fitness*. Users as diverse as a cub scout to a wounded warrior have posted kudos and videos of their various adventures with the Freedom Chair. This recreational vehicle is used to assist a person when they want to camp,

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hike, fish, or participate in marathons. Current users range in age from 8–94 years old.

To operate The Freedom Chair, the user manipulates the two, two-foot-long, large levers. The levers utilize larger muscle groups making it ergonomically feasible to operate and 75% faster than a standard push rim wheelchair. Users are in the equivalent of first gear when they place their hands at the top of the lever. If hands are placed near the bottom, then the user is automatically shifted to a harder, faster gear. The large wheels operate like a mountain bike. The third wheel is in front of the footrest helps to balance and navigate through obstacles, such as puddles and mud. It requires power to operate it – muscle power – supplied by the user to propel forward.

As a wheelchair user, I was excited to try out the chair. I rented it for a week and I was told that up to \$375 of the rental cost could be applied to my purchase. For me, the main attraction of the Freedom Chair is, users can sit at a natural body angle to propel it forward. Sitting at the angle required to propel a standard wheelchair aggravates my chronic back pain.

Before I rolled the fully assembled Freedom Chair into my Van, co-founder Mario Bollini, gave me a crash course in operating the “mountain bike wheel chair.” To turn, you operate the levers like the oars of a boat – holding one lever still and pumping on the other. It takes practice, but before I departed I was soon comfortable and confident.

I am an avid hand cyclist so I am not afraid of a cardio workout, but compared to the energy needed to operate a standard wheelchair, this was a piece of cake! After the first day my back was sore, but only because I was engaging core muscles that I do not use every day. On the second day, I began developing muscle memory; I was not sore and my my back was not stressed or angry. I have Multiple Sclerosis and fatigue is a common symptom, so on third day I rested. After all, most people do not mountain bike three days in a row. I successfully navigated streets, sidewalks, and curb cuts. I only needed assistance once when I encountered a steep bump. A friend jumped in to give me a gentle push using the buddy handles. On the last day of the rental, I went grocery shopping and rolled through the aisles of the stores with ease.

The designers have truly developed the Freedom Chair with ergonomic and financial sensitivity that people with many different types of disabilities will benefit from. All of the moving parts can be found at a bike shop, making maintenance economically feasible. The Freedom Chair also disassembles,

making it easy to store in the trunk of a car. Ben Judge from Product Development disassembled the chair in less than 30 seconds! The cost of the Freedom Chair is \$2995, which is less than half of similar off-road devices. Recognizing that cost may be an obstacle, multiple finance and payment options are provided on the Financing section of the GRIT website.

When I returned the Freedom Bike, I entered the crowded GRIT office to give positive feedback from my adventure and make a suggestion for improvement – adding a basket or storage pouch. I was pleased to hear that it is already in production. I also shared my experience of riding the bike and meeting strangers who expressed their respect. One person said “I wouldn’t want to arm wrestle you!” Nerissa Cannon, Administrative Assistant and fellow wheelchair user, has had similar experiences and said “people look at me with awe rather than pity.”

The GRIT team was helpful and supportive. They hope to build a Boston based Freedom Chair team of athletes, proving that “Empathy is one of the greatest creators of energy!” as stated by Angela Ahrendts, Sr. Vice President of Apple.

Let your adventure begin. Go GRIT!

For more information, visit www.gogrit.us

Mary Jane Fietze has been living with Multiple Sclerosis for 24 years. She writes for The Burlington Union about disability topics. She has won several awards in hand cycling.



Photos: Courtesy of gogrit.us

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 in Charlestown, which is a national model for environmental and inclusive design as well as Spaulding Rehabilitation Hospital Cape Cod, Spaulding Hospital Cambridge and two skilled nursing facilities, as well as twenty-five outpatient sites throughout Eastern Massachusetts. Spaulding strives to continually update and improve its programs to offer patients the latest, high-quality care through its leading, expert providers. Spaulding has been awarded a Model Systems designation in three specialty areas- Brain Injury, Burn Injury Rehabilitation, and Spinal Cord Injury - by the National Institute on Disability, Independent Living, and Rehabilitation Research. Spaulding is a teaching hospital of Harvard Medical School as well as the official rehabilitation hospital of the New England Revolution. 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 #5 ranking in 2016-2017. For more information, please visit www.spauldingrehab.org.

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From the Editor

Dear Readers,

Enhancing accessibility and social inclusion opportunities for people with disabilities to participate in community life is continually improving, and it's frustratingly slow. Perhaps part of the slowness is because we are looking at accessibility through the lens of making 'accommodations' solely for people with disabilities.

A consequence of seeing the need for accommodations solely through the lens of disability is, people tend to only make an effort when they have the time, need, inclination, or legal requirement to do it. It also means that people with disabilities are put in the position of being perceived as the only group that benefits from accommodations.

The truth is, many people benefit when access is designed for all – older people, mothers, children, the unemployed, the homeless... I know I'm preaching to the choir on this, but it's helpful to keep this 'truth' front of mind as people with disabilities continue to advocate for accommodations. It's not just inclusion for 'Us,' it's inclusion for 'All.' Alternatively, local communities benefit from a higher level of social engagement of diverse groups of individuals. We each bring strengths, contributions, perspectives, and skills that are too valuable to be absent from all aspects of community life.

Fortunately, there are many creative individuals, organizations, and state-funded programs that are working collaboratively with people in the disability community to create opportunities for greater social inclusion. In this issue, we offer you a variety of innovative approaches and partnerships that are working to create inclusion for all – in restaurants, bars, housing, exercise, recreation, and on off-road excursions.

Marianne DiBlasi, Editor

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Photo: Courtesy of msktc.org

strategies for exercising after burn injury. In addition to the main video, the module includes short clips that highlight various components of burn injury and exercise, ranging from the role of peer support to amputation to competitive sports. Videos are accompanied by a fact sheet and slideshow that offer practical tips for exercising after a burn injury. The fact sheet is available in both English and Spanish. These hot topic module resources are grounded in Burn Model Systems (BMS) research and clinical practice.

“Physical activity is especially important to counteract the effects of hospitalization,” said Dr. Jeffery Schneider, Project Director of the BHBIMS. “Exercise helps fight the deterioration of muscles that can result after prolonged immobility.” Exercise can also help prevent infection, improve flexibility and lower the risk of developing scars or contractures. In addition, it can help breathing, make it easier to accomplish everyday activities and contribute to a sense of well-being.

“Some burn survivors may resist exercise after they’re injured because of concern over additional injuries or pain,” said Amy Acton, Executive Director of the Phoenix Society for Burn Survivors. *The Exercise After Burn Injury* video demonstrates how easing into physical movement can lead to an active lifestyle.

BMS centers are funded by the National Institute on Disability, Independent Living, and Rehabilitation Research. BMS centers provide the highest level of comprehensive and multidisciplinary care, including emergency medical, acute medical and post-acute services. In addition to providing direct services, BMS centers play a pivotal role in building a national capacity for high-quality treatment and research that serve people with burn injury, their families and their communities.

Visit www.msktc.org/burn/Hot-Topics/Exercise to learn more.

Tim Sullivan is Director of Communications, The Spaulding Rehabilitation Network & Partners Continuing Care.

About the Model Systems Knowledge Translation Center

The Model Systems Knowledge Translation Center (MSKTC) is a national center that supports the Model Systems programs in meeting the information needs of individuals with spinal cord injury (SCI), traumatic brain injury (TBI), and burn injury by summarizing research, identifying health information needs and developing and disseminating information resources. The MSKTC is funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR). NIDILRR is a center within the Administration for Community Living, U.S. Department of Health and Human Services. Model Systems are funded by NIDILRR to conduct innovative and high-quality research, provide patient care and offer services to improve the health and overall quality of life of individuals with SCI, TBI and burn injury. For more information, visit www.msktc.org.

About Spaulding Rehabilitation Network

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Micro Housing and Accessibility

By Kathryn Denis

I recently took part in a panel discussion at the Boston Society of Architects (BSA) on micro-units and accessibility. Along with Bill Henning, executive director, Boston Center for Independent Living, Dianna Hu, software engineer at Google, and Michael Muehe, executive director/ADA coordinator, Cambridge Commission for Persons with Disabilities; I facilitated the night's discussion on accessibility in this 'tiny' trend.

I began the discussion by looking at micro-units through a regulatory lens. In Massachusetts, most privately funded multifamily housing projects are required to comply with 521 CMR, Massachusetts' accessibility code, and the design and construction requirements of the Fair Housing Act (FHA). I reviewed two sample micro-units modeled in the BSA One Room Mansion exhibit; the uhü and the 1-bedroom (BDR) micro-unit. The uhü, short for urban housing unit, is a 385 SQFT prefabricated travelling unit developed by the Mayor's Housing Innovation Lab and the BSA. The One Room Mansion 1-Bedroom micro-unit is a diagrammatic simulation of a micro-unit that exists in the BSA Space.

Overall, the units appeared to be meet the FHA and 521 CMR Group 1 requirements. (See link to Architecture Access Board requirements at the end of this article). The units even appeared to meet many of the more stringent 521 CMR Group 2A requirements (see link below), with a few issues residing in the bathroom/ kitchen layouts. For example, the uhü bathroom lacked the required clearance at the toilet, which is a common issue. To make this analysis more engaging, KMA printed full-scale diagrams to place in the 1-BDR micro-unit exhibit. The full scale clear floor space diagrams were printed in green, for compliance, and red, for non-compliance. Seeing the requirements in scale helped people to visualize the design changes that needed to be addressed.

This analysis led to a broader discussion regarding the need for accessible housing in Boston. Dianna and Michael, both chair users, shared personal stories about the difficulties of finding accessible housing. Their stories brought some valuable perspective on the many challenges disabled people face when searching for a place to live. The housing stock in Boston is expensive, old, and often lacks vertical access. Both Dianna and Michael ended up renovating spaces because they could not find units that met their needs. Bill Henning brought up some great points about how cities, which seem to put a lot of focus on affordable housing, need to bring attention to the lack of accessible housing as well. He emphasized the difficulties people with disabilities and people with low income face when trying to find housing.

Personally, I was a surprised with how accessible the micro-units were. Typically, when people think about accessible units they think large and open spaces, not micro-units. However, having gone through the regulatory requirements, it's clear creating an accessible micro-unit is very possible. With a little extra thought and some careful design, perhaps micro-units could help alleviate the need for affordable and accessible housing in the Boston area.

For information on the Architecture Access Board (AAB) requirements, visit www.mass.gov and search "AAB Rules and Regulations."

Kathryn Denis is an Access Planner at Kessler McGuinness & Associates, LLC in Newton, Mass. (www.kmaccess.com) In her role at KMA, Katie focuses primarily on accessibility in multi-family housing. In her spare time she is active with the Habitat for Humanity Metro West/ Greater Worcester Affiliate, providing plan reviews and access input. Her e-mail is kdenis@kmaccess.com.



Photo: Courtesy of architects.org/bsaspace/exhibitions/one-room-mansion

Design Based on Architecture and Lived Experience

By Sandy Alissa Novack

I recently attended a “Lunch & Learn” at the Institute for Human Centered Design in Boston. The presenters were Todd Hanson and Anne Weidman. Todd is an architect who is dedicated to the concept of “experiential research-based design” in healthcare environments. He has spent many days and nights in facilities gaining an appreciation for what people go through in these health care facilities. Anne leads the marketing effort at JSA Inc. Many architects and design specialists attended but even the non-architects, like myself, were eager to hear the perspectives of Todd and Anne on accessible architecture.

Todd presented part one of the “Lunch & Learn” and began by sharing that he loved to run and ran in the Boston Marathon. After 35 years of running, Todd began to notice bodily changes. First there was an odd feeling in one hand so he began seeing specialists. More symptoms started showing up, and eventually, he was diagnosed with Primary Lateral Sclerosis, a rare neuromuscular disease. A transformation began which included visits to a speech pathologist for assistance in how to pronounce words he had previously been able to pronounce. During the Lunch & Learn, Todd used an iPad as a communication device for projecting his voice. He saw himself change from being able to run, to being clumsy, to needing to use a Volaris brand hi-tech walker and cane.

As a walker-user, he began noticing architectural challenges: how heavy doors can be when you are trying to go through them using a walker; out-swinging doors; the tension setting that resulted in some doors closing faster than others causing the faster closing doors to hit him before he was all the way through; protruding door hardware that could easily get caught on his walker causing him to topple over; heavily textured carpets, cobblestones, and other uneven surfaces that were trip and fall hazards.

When the walker no longer provided enough mobility support, Todd said he swallowed his pride and began using a wheelchair. His fear of falling left, but the wheelchair was uncomfortable, difficult to push, and he did not know where to seek advice. His wheelchair challenges included slopes, inadequate clear floor space, difficulty getting leverage from a sitting position to open heavy doors, and getting his chair’s small front wheels caught on broken sidewalks. Despite being 6’2” tall, high shelves were too high to reach.

All of this had social implications, which he shared with us: A loss of independence and the ability to do things on a whim. He also lost a sense of purpose because the things he wanted to do or places to go now seemed out of reach. He was no longer able to go out alone, which led to isolation, especially when his wheelchair would not fit into the entrances of private homes and

restaurants. Todd said, “It wasn’t until I became disabled that I could truly appreciate all that I didn’t comprehend in regards to barriers, accessibility and inclusive environments.”

Todd is now a user/expert as well as a designer, and is principal of JSA, Inc. in Portsmouth, NH where he continues to focus on tailoring environments to meet the physical and emotional needs of varied users. Todd’s talk was unusually sensitively done and relatable by anyone who has experienced their body transform because of a disability. I hope someday he writes a book, articles, or even a blog about his experiences to speak for those who may not be as eloquent about explaining their life changes, but also to document his observations for future architects, designers, and the general public to ponder in their work and day-to-day life.

Todd, along with his colleague and friend, Anne Weidman, are making history in addressing accessibility at restaurants in Portsmouth, NH. Anne presented part two of the “Lunch & Learn” and talked about the needs and desires of people with disabilities to go out and socialize. Together, Todd and Anne conceived of Access Portsmouth, a website that helps people of all abilities know what to expect when they visit Portsmouth, NH. They identified a dozen cultural attractions and 60+ restaurants in downtown Portsmouth to visit and write an accessibility review. Before posting it on the website, reviews are discussed with the business owners and managers to ensure they are accurate and acceptable. The website lists a lot of “secrets” a person with disabilities should know. “There is a lot more accessibility if you know what to ask for”, says Anne, “even something like knowing to ask the manager for the ramp.”

The concept of Access Portsmouth is a template for other towns and cities to replicate. Todd and Anne are happy to report that word is spreading to other states and some locations have contacted them about trying to replicate this service.

For more information about Access Portsmouth, visit www.jsainc.com/access-portsmouth or send an email to info@accessportsmouth.com.

To contact Todd and Anne directly:

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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.



Feel Free to Socialize in an Accessible Environment

by Ms. Love



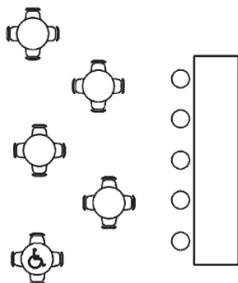
Photo: Courtesy of kmaccess.com

You are having a first date and agreed to meet at a bar in a nearby town for a drink to meet each other without committing to dinner. But now you wonder if that was a good idea. Or maybe your co-worker wants to go for a drink after work

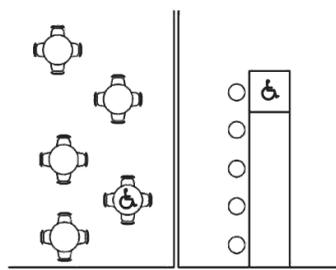
following a tough day and recommends the bar a few blocks away because he says he likes to look at the fish tank at the bar. You want to be social but how is that possible if the bars are not accessible? Glad you asked. Ms. Love will try to help with some assistance from Kessler McGuinness & Associates (KMA) of Newton, MA, a nationally known firm specializing in universal design and accessibility planning. In a recent blog (www.kmaccess.com/accessible-bar-seating-requirements/), KMA posted:

KMA recently clarified the accessibility requirements for dining counters (bar-type). Accessible seating locations at bars are not required if other accessible seating is provided within the same area.

Kimberly Paarlberg, who is Codes and Standards Senior Staff Architect for the International Code Council (ICC), provides clear guidance on the requirements of Section 1108.2.9.1 of IBC in an article, "Are Wheelchair Spaces Required at Bars?" in Building Safety Journal Online. If the bar-type seating is part of the general dining area, or if other accessible seating is provided within the bar area, then the bar itself does not have to provide accessible seating.*



ACCESSIBLE BAR SEATING NOT REQUIRED



ACCESSIBLE BAR SEATING REQUIRED

Given this code, the person who has a colleague that wants to sit literally at the bar so he can eyeball the fish tank, will have to do some research and find out if there is other accessible seating is available within the same area. If there is, the bar is not required to have accessible seating at the bar. If it turns out the bar is not accessible, consider volunteering to scope out another venue that meets your accessibility needs. Your colleague can eyeball the fish another time. After all, he wants to have a drink with you, so he wants you to be comfortable.

If you plan to meet someone for a date, have a list handy of local places you know are accessible and comfortable for your needs so you can suggest a place to meet. However, it's not possible to know about every place in advance. Be upfront and say you would like to call the proposed establishment to ask about bar accessibility. You will get back to them and let them know if it's a go or if you need to discuss other alternatives – meet at an accessible table in the bar area or go to a different establishment.

Most of all, let people know that you are happy to socialize with colleagues or looking forward to meeting someone new, and hopefully special, on a date. Then, you can make the rest of the pieces fall into place. Ms. Love is behind you 100%.

** David Kessler, Principal of KMA, notes, "Ms. Paarlberg's blog/article provides an interpretation of the requirements for accessible seating. As with the adoption of any model code, local amendments and interpretations by local building officials should be reviewed (for the development of any bar project). Careful consideration of operations and policies, as well as architectural elements, is necessary to determine whether accessible seating locations at bar counters are required in any given project". The scenario examples in this article must be interpreted in this spirit. Whenever possible, check the accessibility of a space in advance.*

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 DI.LoveandIntimacy@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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Braille Trail and Sensory Garden

The new **Braille Trail** is a quarter-mile looped trail within the Watertown Riverfront Park, surrounding a specially designed sensory garden, which features a number of structures, such as benches, stone walls, a Mishoon (canoe-like) boat, and a musical marimba bench specifically designed to look like a xylophone to allow visitors to strike wooden slats to play music. The sensory garden's elements incorporate several senses including touch, hearing and smell.

Additionally, the Braille Trail includes a guide wire along the trail to assist visitors with impaired vision. Different types of beads strategically placed along the wire will indicate the location of both Braille interpretative panels and seating. Also along the trail are ten interpretive features on granite posts written in both English and braille.

The Watertown Riverfront Park is located at the intersection of Charles River Road and Irving Street in Watertown, just two blocks away from Perkins School for the Blind.

Enjoy outdoor fun activities this summer

Offered through the Department of Conservation and Recreation's (DCR's) Universal Access Program

Take a seat in a kayak and paddle your way through warm, sunswept afternoons. Cruise along the Quabbin Reservoir, observing the plentiful source of fish and wildlife or flip that kickstand up and go for a bike ride down the rail trail. Take to the green and perfect that golf swing or lace up those boots and go for a gentle hike along scenic trails. Whatever activity you prefer, there's something for everyone, so have some fun in the sun in Massachusetts State Parks this summer!

To view the summer newsletter and calendar of events, visit www.mass.gov/eea/agencies/dcr/massparks/accessibility/ Scroll down to General Information and select "DCR Access News."

If you'd like the newsletter in an alternate format, please contact Laila at laila.soleimani@state.ma.us or 413-545-5759.

