DisABILITY Issues

Providing people with disabilities, their families, friends, and advocates with information, resources, and insights into attitudes to improve the quality of their life, health and employability options.

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TABLE OF CONTENTS

From the Editor | Marianne Dillon
Ready & able: Ensuring Equality in Cancer Care for Patients with Disabilities | Dr. Ronald Berman
Is Ableism a Barrier to Adequate Housing for People with Disabilities | Linda Mezo Kenyon
Stories Inspired by Disability Awareness Months | Marybeth Barker
Myself Gone | Ronald Berman
What I Learned About Life From Becoming Disabled | Penelope Dalton-Smith
Technology: Far Better Up Near Mirror! | Joel Burland
Love & Intimacy Cancer Schedule Fashion & I | Ms. Lisa Bloomquist-Rivera
Fantasy of Electric Fields | Dr. Ben Kachan Abdul Ahad
RNID/NCA Exhibit Explores the Past Experience | Gail Dobbson The Writer
Call Dobbson The Writer!

From the Editor...

Dear Readers,

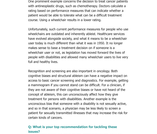
In November, I attended a webinar hosted by WGBH in partnership with the Massachusetts Office on Disability. The webinar was hosted by Colleen who discussed her book, Beyond Limits: Stories of Creative Connection and Broken Stereo. Colleen included that belonging is a human need. Yet, for people with disabilities, it is not. Belonging is to be dared in creative ways. Belonging is dared in ways that encourage increase our sense of well being and self-worth.

Dared to exercise. I've been reflecting on isolation, belonging and how that relates to the disability community. These issues, people with disabilities, have been dared to be creative in finding ways to belong, to housing, to employment, to relationships, to recreation. We are on our own to advocate for and create opportunities where we can belong, be friends, celebrate, and encouraging. I the antithesis of belonging.

Community is the antidote for going it alone. Connecting with others in the disability community which I'm dare to describe as a sense of solidarity and belonging. Having a disability presents unique challenges. Yet, the challenges can be overcome when we create fresh perspectives and creative ways to meet opportunities.

It is with this belief in the power of community that Disability Issues publishes another issue dedicated to the challenges for people with disabilities. We strive to foster a sense of solidarity and belonging. In this issue, you will read about ableism, the impact of personal hand experiences, people who are hard of hearing, deaness, deaf, common Disabilities, and useful resources. We are grateful to Dr. Ron Berman, Linda Mezo Kenyon, Marybeth Barker, Penelope Dalton-Smith, Joel Burland, Lisa Bloomquist-Rivera, Dr. Ben Kachan Abdul Ahad, Gail Dobbson, Ms. Lisa Bloomquist-Rivera.

Marianne Dillon, Editor



Ensuring Equality in Cancer Care for Patients with Disabilities

By Ron Berman, MD

Ron Berman, MD, of the Department of Physical Medicine and Rehabilitation at Cedars-Sinai Medical Center in Los Angeles and Women's Hospital, is a board-certified physiatrist who is also a cancer survivor. Dr. Berman's research focuses on cancer survivor and cost-injury, the cost-injury for personal assistance services and medical background to advocate for greater health equity for people with disabilities.

Dr. Maxwell and others published a commentary in The Lancet Oncology discussing the disparities in cancer care for people with disabilities (Dec. 2019). Maxwell discusses four recommendations for moving this work and five plans for dismantling existing obstacles.

Q: What are some general recommendations for fighting ableism and improving oncology care for persons with disabilities?
Maxwell's recommendations are: 1) Recognize that people with disabilities are stereotypes people and the health care system. 2) Recognize that cancer care is a "complex and multidisciplinary" process. 3) Recognize that people with disabilities are "experts" in managing their disabilities and the quality and care that our clinicians provide, and it's this body to review and learn from. 4) Recognize that people with disabilities have experienced a special cost-injury and are a vulnerable group. 5) Have experienced the healthcare system extensively throughout my life, I'm a cancer survivor, I'm a person with disabilities, I'm a doctor, I also understand how unlike it is that people with disabilities experience differently because of their disability status, and so I have developed a deep personal passion for this type of work.

Q: What are the current issues with ableism in cancer care?
Ableism is pervasive in our society. Clinicians are not immune from ableism with unfortunately stigma, such as the stereotypes. Ableism cascades in rating based on performance measures that can indicate whether a clinician is good or bad, or whether a clinic is good or bad. Ableism causes injury, a detrimental result to a person.

Unfortunately, such current performance measures for people who are cancer survivors and people with disabilities, especially healthcare services have evolved alongside society, and what it means to be a whether person with a disability, or a person who is a "cancer survivor." Ableism creates anxiety to have a treatment decision if it is necessary to whether/per one or not, so legislation has moved forward the law of "Medicaid Buy-In" which allows people with disabilities to be able to have full and healthy lives.

Recognition and screening are also important in oncology. Both cognitive biases and structural ableism can have negative impacts access to basic cancer screening and diagnostics. For example, getting a mammogram or colonoscopy is difficult for people in a wheel chair. Only one out of seven of that population has been screened for breast cancer of ableism, this can unnecessarily affect how they plan treatment, and it affects their quality of life. Ableism is a "cost" or circumstances like that someone with a disability is not sexually active, and so in that scenario, a physician may be less likely to screen a person for STD's, and this can have a negative impact on their life and certain kinds of cancer.

Q: What is your top recommendation for tackling these issues?
In our special issue, we have several recommendations including, "Recognition of Disability Status." Clinicians need to be able to ask about cancer screening recommendations, that can be helpful, it is especially highlight is the effect to increase disability awareness and cultural competency. Clinicians need to be able to ask about disability status, and it's important to be able to ask about disability status, and it's important to be able to ask about disability status, and it's important

What I Learned About Life From Becoming Disabled

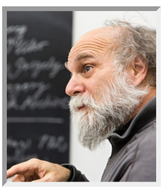
By Penelope Ann Shaw

Twenty-two years ago at 32 years old, I was suddenly disabled. Not only did I have to learn how to live life as an adult this general I learned that medicine is not perfect. Medical professionals don't always make sense of my symptoms. Telling and being unable to tell the difference between what I can do and what I cannot do. I learned that I, not my doctor, is the expert on my life. I learned that I am the Medical Surgeon of my life.

I learned that I can be a complete on my own and was just a tolerance of my disability. I learned that I can be a complete on my own and was just a tolerance of my disability. I learned that I can be a complete on my own and was just a tolerance of my disability.

show, aptly named *A Fashion Revolution*, highlighted innovative work from big-name as well as up-and-coming brands that are making adaptive and universally designed fashion. The models included people with various types of disabilities.

In a first, Victoria's Secret debuted an adaptive line featuring bras, underwear, slips, tights, and more in fun, bright colors true to the brand. The collection became available to purchase in October. Other brands that were featured on the Runway of Dreams included Tommy Hilfiger, Zappos, JCPenny, Target, Steve Madden, Kohl's, Adidas, French Toast Adaptive, and Stride Rite.



MASS MoCA Exhibit Explores the Deaf Experience

In What Way Wham? (White Noise and Other Works, 1996-2023), by artist Joseph Grigley, is a new exhibition at the Massachusetts Museum of Contemporary Art (MASS MoCA) that centers on the deaf experience. The exhibit explores the visual representation of speech and sound in the form of installations, sculptures, photographs, films, and books.

WBUR Arts Fellow Solon Kelleher visited the exhibit and writes about his experience in the article, At MASS MoCA, artist Joseph Grigely shares his experience of being deaf.

The exhibition runs through March 2024.

Get Outdoors This Winter!

Winter is almost here. Time to lace up those skates, put on some skis, strap on snowshoes, and ride a kicksled because DCRs Universal Access Winter Recreation Programs are up and running. There is something for just about everyone at locations across the State. Check out the list of upcoming 2023/2024 Winter Events.

The Universal Access Program (UAP) offers adaptive, accessible programming seasonally at state parks, pools, and rinks. We partner throughout the year with All Out Adventures, Easterseals Massachusetts, Holyoke Rows, and Waypoint Adventure to run our programs. Some of the programs are supported by Spaulding Adaptive Sports Centers.

The structured programs feature adaptive equipment, professional staff, and instruction and support. Friends, family members, and companions are encouraged to take part in programs alongside participants with disabilities.

Registration must be done in advance and varies by event. For questions, contact Teri Koopman at 413-461-7126 or teri.l.koopman@mass.gov.

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