



disAbilities Celebration Connection

WINTER 2013

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A Thousand Pounds of Fruitcake

I spent many hours this past summer, going through 50 years worth of “stuff” in my parents’ house here in Northern Virginia. Among the items I discovered were these two awards, given by Civitan to my father for selling fruitcake – lots of fruitcake! (. . . *insert your favorite fruitcake joke here . . .*)

Civitan, (civitan.org) founded in 1917, is a community service organization, whose mission is to “*build good citizenship by providing a volunteer organization of clubs dedicated to serving individual and community needs with an emphasis on helping people with developmental disabilities.*”

One of the fundraising programs for Civitan was selling Claxton fruitcake. My father, you may remember from my earlier editor letters, was very involved in the local disability advocacy movement in the 1960s and 70s; so selling fruitcake was a serious matter in our house for most of my grade-school years.

But these awards reflect, not only my father’s efforts, but also those of my brother and myself, recruited – I might even say, dragooned – to sell fruitcake the way that

Girl Scouts sell cookies; to the neighbors, at school, and in front of the local grocery store. There was no discussion; it needed to be done to help fund

programs for our brother, Philip, so we did it. We dreaded it but we did it.

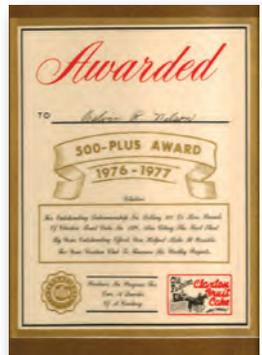
My memories of those years include indelible images of cardboard boxes, packed with 1- and 2- pound bricks of light and dark fruitcake, and stacked to the ceiling in our basement rec room. For years afterwards, the leftover cardboard boxes were used to store the stuff of my childhood; holiday ornaments, games, toys, school projects and so on.

It surprised me to see the dates on these awards because by 1975, my brother and I were both in college, and I have no recollection of selling fruitcake as a young adult. But my father was a consummate

“do it because it needs to be done” man, and so clearly got it done somehow.

These days, at least in Northern Virginia, Civitan runs a monthly flea market as a fundraiser and though Claxton is still a thriving company, I haven’t seen anyone selling fruitcake on the street for many years now. I’m sure that flea markets are a good fundraiser, but I wouldn’t trade my years of selling the dreaded fruitcake for anything.

Laura Nelson, Editor





FINALLY ON FACEBOOK!

*d*isAbilities Celebration Connection and Celebrating Special Children can now be found at <http://www.facebook.com/CelebratingSpecialChildrenInc>

I confess that I am still a complete newbie in the social media forum – and I humbly admit to needing the help of all you facebook aficionados out there!

I invite you to visit our page, LIKE us, submit your timely information and events, and most importantly, make a comment about what we could be doing better.

I look forward to hearing from all of you!

Laura Nelson, Editor

WRITERS WANTED

*t*he *disAbilities Celebration Connection* quarterly newsletter currently has two wonderful writers, Carrie Smoot and Gregg Donaldson, who both contribute on a regular basis. Past issues have also included parents and professionals who have written about their battles won and lost, as well as their hopes and dreams for the future.



But there is always room for additional viewpoints and stories; I invite you to submit yours. Use the CONTACT US feature on the website's homepage to contact me for details. If your article is accepted for publication in the newsletter, I will edit it (after all, it is what I do!), and pay you \$100.

Happy writing!

Laura Nelson, Editor

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Questions? Comments? Please
use the **CONTACT US** form at
www.celebratingspecialchildren.org



**Supporting Virginians' efforts
to secure independence and employment**

DARS

**VIRGINIA DEPARTMENT FOR AGING
AND REHABILITATIVE SERVICES**

Message from the Commissioner



Our Commonwealth now benefits from a new agency—DARS. The agency was created by merging the former Department of Rehabilitative Services and Department for the Aging. In 2013, the adult services units from the Virginia Department of Social Services will become part of DARS.

DARS' merger was proposed by Gov. McDonnell and took effect on July 1. We provide and advocate for the highest quality of services to help older Virginians and those with disabilities to maximize and secure their employment, independence and full inclusion into society and guide the Commonwealth in preparing for an aging population.

At the state level, this new agency will work with its community partners to be more effective in strategic planning, budgeting, program monitoring and evaluation and training and technical support.

The agency will be at the center of the Commonwealth's response to two critical emerging issues.

Many Virginians who are often referred to as "boomers" or "seniors" are in, or are approaching, their retirement years. They rightly expect to be secure in their efforts to age in place and to have safe options for their long-term care needs. DARS will be there for them. Virginia is also committed to having livable communities for those Virginians with disabilities who are transitioning from institutions to community settings or those who wish to live and work with long-term supports and services.

About 12 percent of Virginians are age 65 and older, with the number of older Virginians expected to double to 1.8 million by 2030. About 20 percent of the population is estimated to have a disability at some point in their lifetime.

Your new agency, DARS, will work with these individuals and their families to realize this vision of increased options for adults and a true "Commonwealth of Opportunity" for all.

—Jim Rothrock, Commissioner



Contact us
Toll Free Phone: 800-552-5019
Toll Free TTY: 800-464-9950
E-mail: [Front Desk](#) | [Webmaster](#)

Visit us
www.vadars.org
www.facebook.com/vadars

continued next page



Frequently asked questions about DARS

1. What is DARS?

The Virginia Department for Aging and Rehabilitative Services was created by legislation signed this spring by Gov. McDonnell to take the programmatic units of the current Department of Rehabilitative Services (DRS) and the Virginia Department for the Aging (VDA) and create a new entity with a wider menu of service options. In 2013, the adult services units from Virginia's Department of Social Services will become part of the Department for Aging and Rehabilitative Services, or DARS.

2. What does DARS do?

In partnership with older Virginians as well as Virginians with disabilities and their families, DARS supports Virginians' efforts to secure independence and gain employment; provides and advocates for the highest quality services that empower individuals to maximize their employment, independence and full inclusion into society; and guides the Commonwealth in preparing for an aging population.

3. How do I learn if I'm eligible for DARS' services?

If you're 65 or older, you have company in Virginia. Nearly 1 million Virginians are 65 and older, a number that will double by 2030 as the Baby Boom generation heads toward traditional retirement age. If you're an older Virginian, click here for more information about our services. About 20 percent of people experience a disability, whether through a chronic illness or a physical or cognitive disability, at some point in their lifetimes. If you're an adult Virginian with a disability, click on the links below to learn more about:

[Employment services](#)

[Community-based services](#)

[Assistive technology/devices and equipment](#)

[Disability determination](#)

4. I'm already a DRS client / I already receive services through my local Area Agency on Aging. What's changing?

DARS will focus on improving the response to seniors and Virginians with disabilities who need some aid in maintaining their options for independence, safety and employment. Services such as programs that help older Virginians learn to manage chronic disease will continue to be offered through local AAAs. Consumers who received vocational rehabilitation services, community-based services or other services from DRS will continue to connect with those programs through the field offices, vocational counselors and other personnel. Whether you're an older Virginian or someone with a disability, DARS will support your efforts to secure independence and gain employment. Nothing is intended to interfere with your current receipt of services in your locality.

5. How do I learn about DARS' activities and events?

Click on the links below for more about:

[DARS offices](#)

[VDA boards](#)

[DARS boards and councils](#)

[Area Agencies on Aging](#)

[DARS calendar](#)



Sharing Caregiving Experiences

By Carrie Smoot

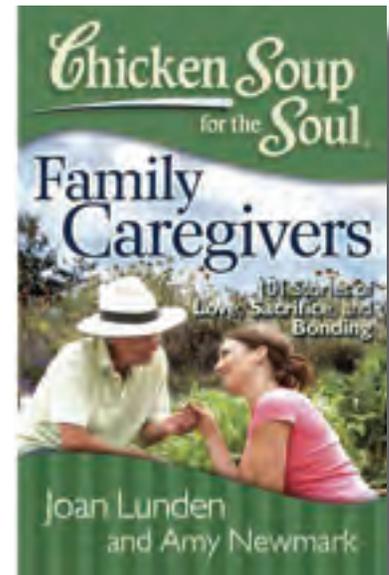
At any time, a parent, child, sibling, spouse, or other relative will face a serious illness or disability. It may occur suddenly, or the person may deteriorate over several years. They will be profoundly changed in some ways, but many times family members will still see their loved one's personality, essence, and soul shine through. Inevitably, that family member will need assistance with activities of daily living, emotional support, and more.

Overnight, those closest to them become caregivers. Most people have no formal training in how to do this; they just see that the person needs help and they offer it willingly, when needed, out of love. Families come in all shapes and sizes, and they are each other's support system. In this process, no one needs to worry about being perfect or doing it all alone. Everyone does the best they can under stress. Each day is an opportunity to choose to practice patience—even though we all fall short. Yes, the "new normal" is very difficult for family members, but it's even more so for the person who is living with a chronic illness or disability.

If you or someone you know is in a caregiving role, an excellent resource is *Family Caregivers: 101 Stories of Love, Sacrifice, and Bonding*, by Joan Lunden and

Amy Newmark. Published in 2012, it is one of the latest in the Chicken Soup for the Soul® series. Readers will find the essays inspiring. More than that, as the men and women who are caregivers—both those who are well known to the public and those who are not—share personal stories, readers can take away ideas, advice, and new perspectives and resources that they can apply to their specific situations.

Throughout the book, Joan Lunden includes insightful question-and-answer interviews with caregivers. Much of the book covers eldercare issues. However, caregivers and their family members can be any age and in any circumstances. In one example, a young woman in her twenties assumed primary responsibility for her grandmother's care, which she termed "a crash course in gerontology." The two were always close, and the experiences eventually led the young woman to pursue a doctorate in the field of aging, which her grandmother championed. In another story, a man relates how he created a "spa day" for his mother, and how much she enjoyed it. Along the way, he discovered meditation as a way to help him deal with overall stress. He introduced the practice to his mother, and it helped her be less angry at the world.



Several stories deal with caring for family members with autism, schizophrenia, and other disabilities and health conditions. One young woman relates how, when she was very young, her role was to cheer on her father, who had become paralyzed. She would look up at him through the Stryker frame, just talking to him and sharing drawings and other craft projects. She was so happy when she made him smile. Once he came home from the hospital and as she got older, her responsibilities changed. Ultimately, she realized there were some things that her father would never be able to do, but she valued what he could do.

All the book's contributors stress how critical it is to make future plans BEFORE a crisis happens. This means asking your family members questions about health records, medical directives, wills, bank accounts and other financial

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statements, powers of attorney, funeral plans, and so on. Family members need to know where these records are kept and how they can access them in an emergency. Conversations about moving into assisted living, a nursing home, a condo, or apartment and leaving the family home can be painful. Illness, obvious slowing down, memory issues, and medical emergencies are very difficult to talk about, but these conversations are important to have while a person is in relative good health. It never hurts to ask and to continue bringing up matters of concern—even if a loved one doesn't want to hear it. Be alert to the changes that you see in someone.

Whenever possible, families need to work together to provide care and advocacy, putting egos aside. Caregivers who shared their experiences for the book noted that delegating tasks and coordinating care was helpful, as well as working in shifts. Others warned

against trying to do everything alone. One writer learned the power of simply asking, "Can you help me?" to everyone she knew when her mother was ill. Not only did this lighten her load, it also gave other people the joy of helping out and the opportunity to spend some time with someone they cared about.

It's critical to make future plans BEFORE a crisis happens. Family members need to know where vital records are kept and how to access them in an emergency.

Several writers shared how role reversal in caregiving affects each person. It takes some time to get used to the new dynamic. Some people eventually accept it, but others do not. It takes awhile. Let your family member do what he or she can independently, but

also stand ready to step in and help. Other people stressed how important it is to continue to love your family member in spite of the changes in him or her, accepting them where they are. It is vital, they say, never to lose the connection to family.

Family Caregivers is not an easy read even though it isn't a technical or medical manual.

Caregiving, by its very nature, is a tough journey. Through it all, the contributors describe how the experience changed them, and how, in some cases, it brought family members closer together and repaired relationships. They also stressed how precious time is, and how it is still okay to be happy and share good experiences in the middle of difficult times. ■

Carrie Smoot is a Northern Virginia freelance writer.

Additional Resources

- *National Alliance for Caregiving* – www.caregiving.org
- *Family Caregiver Alliance* – www.caregiver.org/caregiver/jsp/home.jsp
- *Caregiver Action Network* – <http://caregiveraction.org>
- *Family Caregiving 101* – www.familycaregiving101.org
- *Taking Care with Joan Lunden* – www.rl.tv/shows/taking-care-with-joan-lunden



UNIVERSAL DESIGN

Editor's Note:

Whenever I'm asked what is Universal Design, my favorite quick answer is to describe the entranceway to Walmart. It's all one level from the parking lot into the store; you don't have to go to the end of the walkway to find an accessible ramp. In my opinion, this simple design exemplifies Robert Mace's original definition [Center for Universal Design (1997)]: *"The design of products and environments to be useable by all people, to the greatest extent possible, without the need for adaptation or specialized design."*

This concept can be applied, not only to spaces/environments and objects, but also to education and learning. The information and websites listed below on this page and the next, speak to these two aspects of the concept.

Universal Design for Learning (UDL) . . .

is a set of principles for curriculum development that give all individuals equal opportunities to learn.

UDL provides a blueprint for creating instructional goals, methods, materials, and assessments that work for everyone – not a single, one-size-fits-all solution but rather flexible approaches that can be customized and adjusted for individual needs.

U.S. Department Of Education-Funded Centers That Support UDL

Projects listed below are funded by the U.S. Department of Education. Many are projects affiliated specifically with the Department's Office of Special Education Programs' Technical Assistance and Dissemination (TA&D) Network.

www.osepideasthatwork.org/udl/pdf/fundedctrs.pdf *

- ***The ACCESS Project – Colorado State University***

<http://accessproject.colostate.edu/>

Offers information and resources about Universal Design for Learning (UDL). The ACCESS project is a professional development initiative to infuse UDL philosophy, content, and instruction into faculty professional development at the postsecondary level. The project provides information about UDL, a series of UDL modules, and a section on research being conducted at the university regarding the use of UDL in classes.

- ***Center for Implementing Technology in Education (CITEd)***

www.cited.org

CITEd was created to support state and local education agency leadership to enhance the use of technology to support students in achieving positive education outcomes. CITEd's Web site contains a variety of external resources related to UDL.

- ***National Instructional Materials Accessibility Standard (NIMAS)***

<http://nimas.cast.org/>

Operates two national centers to further develop and implement the National Instructional Materials Accessibility Standard (NIMAS). The NIMAS guides the production and electronic distribution of digital versions of textbooks and other instructional materials so they can be more easily converted to accessible formats, including Braille and text-to-speech.

- ***Center for Applied Special Technology (CAST)***

www.cast.org

Offers information related to Universal Design for Learning, including publications, products, and professional development resources.

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UNIVERSAL DESIGN continued . . .

* 7 Principles of Universal Design...

1. The design can be used by, and marketed to, all kinds of people.
2. The design incorporates a wide variety of preferences.
3. The product or service is easy to understand and use.
4. It works in all kinds of settings.
5. The design accommodates error.
6. The product or service requires minimal effort to use.
7. It accommodates variations in size and position.

* www.ncsu.edu/www/ncsu/design/sod5/cud/pubs_p/docs/poster.pdf

Assistive Technology Websites

Additional information can be found under the Community Resources TAB on the Celebrating Special Children website.

• **Abledata**

Contains information on more than 40,000 assistive technology products sorted by 20 categories.
www.abledata.com

• **Adaptive Access Company**

Accessible construction and safety equipment
www.adaptiveaccess.com

• **Assistivetech.net**

Web resource for assistive technology (AT) with links to a wide variety of AT and disability-related information.
www.assistivetech.net

• **AssistiveTechnology Loan Fund Authority (ATLFA)**

A low interest loan program that assists Virginians with disabilities to get the assistive technology they need. Also provides Telework loans for individuals working from home who need equipment for their home business.
www.atlfa.org

• **Center for Universal Design**

National information, technical assistance, and research center that evaluates, develops, and promotes accessible and universal design in housing, commercial and public facilities,

outdoor environments, and products. Works to improve environments and products through design innovation, research, education and design assistance.

www.ncsu.edu/project/design-projects/udi/center-for-universal-design/

• **Family Center on Technology and Disability**

Online resource designed to support organizations and programs that work with families of children and youth with disabilities. Offers information and services on the subject of assistive technologies. Extensive listing of resources.
www.fctd.info

• **Rehabilitation Engineering and Assistive Technology Society of North America (RESNA)**

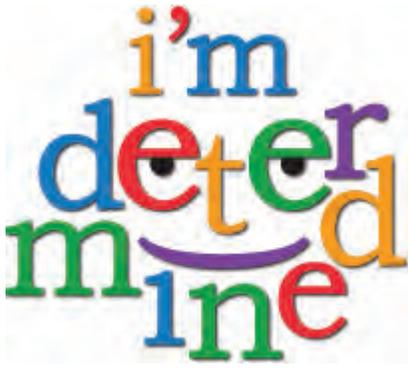
An interdisciplinary association of people with a common interest in technology and disability whose purpose is to improve the potential of people with disabilities to achieve their goals through the use of technology.
www.resna.org

• **Rehabilitation Equipment Exchange Network**

Free service to facilitate the exchange and transfer of used rehabilitation equipment.
www.rehabequipmentexchange.com/index.html

• **Virginia Assistive Technology System**

Statewide project committed to improving the quality of life for all Virginians by increasing awareness and accessibility of assistive technology.
www.vats.org



2013 Youth Summit Application

The Virginia Department of Education's **I'm Determined** project, in conjunction with the Partnership for People with Disabilities, invites applications for sponsorship to the 7th Annual I'm Determined Youth Summit at James Madison University in Harrisonburg, Virginia.

Youth with disabilities from across the Commonwealth will meet to identify ways to become better advocates and lead more self-determined lives. The selected individuals and a parent/guardian will receive paid registration, dormitory accommodations, travel expenses and meals for the three-day event. A concurrent Parent Summit for the selected participant's parent/guardian will be held at the university.

The Youth Summit will start on Wednesday, June 19, 2013 and will end on Friday, June 21, 2013. More detailed information regarding the Youth Summit and Parent Summit will be provided upon acceptance of the youth.

- We will accept the first 200 qualified applicants
- Deadline for submission of applications is Friday, March 22nd, 2013 or when the 200 applicant limit is reached (which ever happens first).
- Selected youth will be notified prior to April 15th, 2013.
- NO ACCEPTANCE LETTER WILL BE MAILED.
- Accepted youth or youth's parent will be notified by phone call and/or email.

LOCATION

James Madison University
Harrisonburg, VA 22807

For information about past Youth Summits visit www.imdetermined.org

Application Criteria:

- Young person with a disability, 14 years and older at time of Summit
- Young persons under age 18 must have a parent/guardian attend

Application Instructions:

- Complete the application form found at www.imdetermined.org/news/2013_youth_summit and upload your essay, slide presentation or video.

Questions?

Contact Kim Sheridan at (540) 831-7159 or e-mail: imdetermined.vdoe@gmail.com

YOUTH ESSAY

Everyone has a unique story; every story is important. We'd like to hear yours. Please respond to the following questions. You may submit a written essay, PowerPoint presentation OR a video response. If you are submitting a video response, it MUST be in an mp4 format.

- *How has having a disability impacted your life? Some areas to cite may include – but are not limited to – personal and social, academic (school), goal-setting and independent living. What strategies do you use to help you in areas that are a challenge?*
- *Explain a point in your life where you were forced to make some hard decisions about how you viewed and dealt with your disability. How did the decisions you made demonstrate self-determination? How do you use self-determination in your life, both your personal and school or career life?*

The Youth Summit will start on Wednesday, June 19, 2013 and will end on Friday, June 21, 2013. Deadline for submission of applications is Friday, March 22nd, 2013 or when the 200 applicant limit is reached (which ever happens first).

For more information visit www.imdetermined.org

Employment Opportunity

Vacancy Announcement: Executive Director, National Council on Disability

Series & Grade: AD-0301-00

Open Period: January 17, 2013 until Filled

Position Information: Full-Time Excepted Service

Duty Location: Washington, DC

Key Requirements: You must be a US Citizen or National



The National Council on Disability (NCD) invites qualified individuals to submit applications for consideration to be appointed as the NCD Executive Director. NCD remains committed to actively recruiting and retaining qualified people with disabilities and encourages qualified people with disabilities to apply for the Executive Director position.

NCD is an independent federal agency charged with advising the President, Congress, and other federal agencies regarding policies, programs, practices, and procedures that affect people with disabilities. The Executive Director is responsible for overall day-to-day management of the agency and expected to serve both as a substantive leader regarding NCD's policy work and be ultimately responsible for various executive functions required of all federal agencies. NCD's Bylaws, Strategic Plan, and budget information are available at www.ncd.gov/Accountability.

The ideal candidate for Executive Director will be an individual who is (1) deeply experienced in disability policy issues and well-positioned to become the substantive policy leader and public face of NCD, (2) knowledgeable and experienced in management of a federal agency, including all aspects of personnel management and preparation of annual budgets and written justifications to the U.S. Office of Management and Budget and U.S. Congress, and (3) an effective communicator and coalition-builder who can work effectively with NCD's stakeholders, the White House, Administration, and Congress.

Candidates should meet the U.S. Office of Personnel Management's Executive Core Qualifications, which are available at www.opm.gov/ses/recruitment/ecq.asp. Your resume must demonstrate your experience, accomplishments, training, education and awards reflecting your ability to meet each of the executive core qualifications. Compensation and benefits for the Executive Director position are comparable to Level IV of the Executive Schedule.

How to Apply:

Inquiries and applications should be addressed to Jonathan Young, Chairman of the National Council on Disability, and either emailed to NCD@NCD.gov (with a subject line of ED Application) or mailed to NCD at 1331 F Street, NW, Suite 850, Washington, DC 20004. Applications should include (1) a cover letter summarizing an individual's qualifications for, interest in, and vision for being NCD Executive Director, (2) a resume specifically developed to demonstrate qualification for serving as the next Executive Director, and (3) references. To ensure consideration for the position, prospective applicants are encouraged to submit their cover letters and resumes as soon as possible.

How You Will Be Evaluated:

Step 1: Resume Screening

Step 2: Structured Interviews to determine Best Qualified (BQ) Candidates

Step 3: Selection by the Chair, NCD.

***Note: Interviews will begin in February and continue until the position is filled.**

Reasonable Accommodations: NCD provides reasonable accommodation to applicants with disabilities, with sufficient notice. If you need a reasonable accommodation for any part of the hiring process, please contact NCD@NCD.gov.

EEO Policy Statement: The United States Government does not discriminate in employment on the basis of race, color, religion, sex (including pregnancy and gender identity), national origin, political affiliation, sexual orientation, marital status, disability, genetic information, age, membership in an employee organization, retaliation, parental status, military service, or other non-merit factor.

2013 National Health Observances

Please visit <http://healthfinder.gov/NHO/nho.aspx?year=2013#top-of-page>
for a complete calendar of observances

Source: *2013 National Health Observances, National Health Information Center, Office of Disease Prevention and Health Promotion, U.S. Department of Health and Human Services, Washington, DC.*

February

AMD/Low Vision Awareness Month

Prevent Blindness America
www.preventblindness.org

1 ~

National Wear Red Day

National Heart, Lung, and Blood Institute Health
Information Center
www.nhlbi.nih.gov/health/hearttruth

14 ~

National Donor Day

Division of Transplantation, Healthcare Systems Bureau
Health Resources and Services Administration
U.S. Department of Health and Human Services
www.organdonor.gov

March

National Kidney Month

National Kidney Foundation
www.kidney.org

National Nutrition Month

Academy of Nutrition and Dietetics
www.eatright.org/nmm

Trisomy Awareness Month

Support Organization for Trisomy 18, 13 & Related
Disorders
www.trisomy.org

11-17 ~

Brain Awareness Week

Dana Alliance for Brain Initiatives
www.dana.org/brainweek

14 ~

World Kidney Day

International Society of Nephrology
www.worldkidneyday.org

11-17 ~

American Diabetes Alert Day

American Diabetes Association
www.diabetes.org/in-my-community/programs/alert-day

April

National Autism Awareness Month

The Autism Society
www.autism-society.org/about-us/national-autism-awareness-month/

Occupational Therapy Month

American Occupational Therapy Association
www.aota.org

29 - May 3 ~

Air Quality Awareness Week

National Oceanic and Atmospheric Administration
National Weather Service
Office of Climate, Water, and Weather Services
www.airquality.noaa.gov

7 ~

World Health Day

Pan American Health Organization
WHO Regional Office for the Americas
www.who.int/world-health-day/en/