

A Report on Disabling Childhood Asthma

The following article is adapted from an Issue Brief published by the NRH Center for Health & Disability Research.

This issue brief describes disabling childhood asthma as a major public health problem, one that challenges the medical community and society to address the comprehensive, continuous health care and rehabilitation needs of children with asthma.

Asthma is growing in prevalence among all children under the age of 17, but it is also unevenly distributed across income groups, and across families living in urban versus rural environments. If untreated, severe asthma is a life-threatening condition. Poorly controlled asthma may result in avoidable hospitalizations and emergency room care, and may have life-long disabling consequences.

Asthma is the fastest growing chronic disabling condition in children.

- Asthma is a chronic inflammation of the airway system due to airflow obstruction.
- The number of children with disabling asthma under 17 years of age has nearly doubled within the last two decades to nearly 1 million children.
- Boys are more likely to be diagnosed with asthma than girls.
- Between 5 and 10 percent of children under 17 have asthma in the United States.

- Asthma is more common in children than it adults.
- Asthma is triggered by a variety of factors. The living environment plays a crucial role in the development of asthma. Among the known allergens are dustmites, cockroach and mouse droppings, and nicotine.

- Unhealthy behavior (e.g. lack of physical exercise) associated with the increase of other chronic conditions (such as diabetes and hypertension) may also have a role in asthma. These other behaviors may lead to exacerbated symptoms with potentially disabling consequences, if not addressed.

- There is no cure for asthma and the cause of the disease is unknown.

Asthma causes multiple impairments.

- Almost 14 percent of children with asthma have functional limitations in the areas of walking, crawling and playing.
- More than 10 million school days are missed annually due to asthma.
- Nocturnal asthma is associated with impaired cognitive functioning and fatigue due to sleep deprivation.
- Severe asthma can result in

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HAIL TAXI !

Wheelchair accessible taxi cabs have proven their worth in Boston. These now familiar accommodations first appeared in January of 1993. By the end of that year there were 40 accessible taxis serving Boston. In June, the Boston Police Department Hackney Carriage Unit auctioned 28 additional medallions for accessible cabs. This will bring the number of accessible cabs in Boston to 78, one of the largest such fleets in the country.

While these cabs have proved popular for travelers with baggage and groups seeking a little extra room, they exist primarily to serve people using wheelchairs. Remember, the medallions for accessible cabs are sold at a significant discount compared to those for the more familiar cabs. This is to compensate for a few special regulations of which you should be aware.

All Boston taxi companies with 15 or more cabs are required to

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INSIDE

FROM THE CENTER
FROM OUR READERS
HOW TO FIND WHAT
YOU NEED

Summer 2001

We are living in what many call "the information age," with reported ubiquitous access to the internet and its on-line data. You might think this would be seen as beneficial by an organization called the Information Center for Individuals with Disabilities. However, this is not altogether the case.

The presumption that the advent of the internet has, or shortly will, solve all the information demands of Americans obscures both the true information needs of people living with disabilities and the real-world access to life-enhancing resources.

Enter "disability" into any of the popular search engines on the internet and hundreds of thousands of hits will promptly appear with little or no clue as to which ones, if any, will provide useful information on the subject of your concern. Successful searching on-line requires either unlimited time, unusual good luck, or a level of knowledge of the subject that is inconsistent with the real situation of families and individuals facing disability for the first time.

The word interactive is constantly applied to computers today. You can not compare the interaction of a computer user with the internet to the interaction of one human being with another. People seeking information about disability or solutions to new challenges of daily life, face a situation in which, by definition, they do not know where to look, exactly what to ask, or even the language in which the subject is often addressed. In the real world there will always be a need for access to an informed and empathetic human being who can engage in conversation, elicit clarification of the exact problem to be addressed, explain options, translate the jargon of disability, and direct people to the many resources available to help them empower their lives.

Over the years thousands of people have called the Information Center and asked, "Can you send me all the information you have on disability?" My usual answer: "When can your truck be here?" The point is, information services are not huge volumes of data, be they in a library or a database. Information services are the interface between the problems you need to solve and the appropriate information required to help you solve them.

Information is critical but the internet is not the answer, it is just another tool. The answer, we believe, is the provision of true information services. You can help to see that these services are maintained and not destroyed by an unrealistic reliance on technology alone.

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President: Nancy C. Schock

Editor: J. Archer O'Reilly III

Death in the Family

Accent on living, started by Raymond Cheever in 1956, was one of the oldest magazines for the community of people living with mobility-related disabilities. The Information Center has been recommending this publication for many years. It is with regret that we note that *Accent* has published its last edition this summer.

Mr. Cheever's wife and daughter are no longer able to keep this wonderful little magazine going. We thank them for all the effort they have given over the years. Subscribers will, hereafter, receive *Paraplegia News*, an even older publication, in place of *Accent*.

Betty Garee has been editor of *Accent* for the past 25 years. She is starting a new quarterly magazine called *SpeciaLiving* that will have the same format and cover similar subjects as *Accent* has over the years. She has said, "With a prayer and your support, I am confident *SpeciaLiving* can be successful and serve your needs for information about special products, entertainment and inspiration that you have come to expect from a magazine for disabled people."

Accent readers will not automatically receive this new publication. To see what Ms. Garee is offering in her new magazine, subscribe, or request a sample issue of *SpeciaLiving*, by writing to: *SpeciaLiving*, P.O. Box 1000, Bloomington, IL 61702; or e-mail SpeciaLiving@aol.com.

You may also visit the website at www.SpeciaLiving.com.

Employment & Health Care: New Office Willing to Work

Often all that stands between a person with a disability and a good job is a part of the medical industry. It may be a medical professional or a stubborn regulation or simple ignorance which keeps the right person and the right job apart. It has taken a long time for the nexus of health care and employment to be addressed systematically.

A new office to assist persons with disabilities gain and maintain competitive employment is scheduled to open this summer as part of a four-year, \$4.3 million federal grant called the Massachusetts Medical Infrastructure Grant (MMIG). The Office of Health Care Coordination, a collaborative effort of the Massachusetts Division of Medical Assistance and the University of Massachusetts medical school, will assist people with disabilities in the following ways:

- Fill existing gaps in the current Medicaid system by improving access to health insurance and health-related services;
- Expand awareness among medical providers, employers, and consumers about ways to enhance and evaluate work capacity; and
- Facilitate communication among consumers, employers, and health care professionals to improve employment outcomes.

The MMIG is authorized by the federal Ticket to Work and Work Incentives Improvement Act (TWWIIA) and funded through the Health Care Finance Administration (HCFA). All 50 states were eligible to apply for grant monies and 25 received some support. Massachusetts was one of two states to receive full funding

because of the strength of the CommonHealth buy-in and other programs that the Division of Medical Assistance has created.

Massachusetts is one of a few states focusing on evaluating what is working with current programs and identifying opportunities for improvement. The initial step in the MMIG was to convene groups of stakeholders, in an advisory capacity, to get feedback on ways that the Office of Health Care Coordination can facilitate the delivery of existing services and benefits to more effectively support persons with disabilities in their working lives.

In December 2000, a group of state agencies met to form the Interagency Advisory Group (IAG). In April a group of persons in leadership roles in disability advocacy organizations met as the Consumer and Advocacy Advisory Panel (CAAP). Most of these members are persons with disabilities. The next group to meet will be the Professional Advisory Group (PAG), consisting of employers and professionals working to help persons with disabilities find jobs. None of these groups are exclusive and may contain some overlapping members. [*Several members of the board of the Information Center are actively participating on these advisory panels as representatives of various groups and organizations.*]

Another part of the MMIG is to form state-to-state partnerships to help other states receive and provide technical assistance in the design and implementation of Medicaid programs. These partnerships will establish policies to improve health and employment

outcomes for persons with significant disabilities and share what is discovered to be the best practice with state partners across the country. In addition, the MMIG will conduct a number of monitoring and evaluation projects to help improve current programs and establish more effective health care services to assist persons with disabilities gain and maintain their employment goals.

Co-directors of the MMIG are Jay Himmelstein, MD, MPH, Director of the University of Massachusetts Medical School's Center for Health Policy; and Ellie Shea-Delaney, MPA, Director of Plans for the Elderly and Disabled at the Massachusetts Division of Medical Assistance. Anyone needing more information on the MMIG can call Leslie Olin at (508) 856-4039 or e-mail Leslie.Olin@umassmed.edu.

Recruiting is underway to fill staff positions for this office. Anyone with an interest and experience working in this area who would like further information regarding available positions may contact Sylvia Spencer at (508) 856-4226 or e-mail sylvia.spencer@umassmed.edu.

Back issues of
Disability Issues
are available on-line
at the
Information Center's
web site at
www.disability.net.

'Toolbox' for Farmers with Disabilities

Farming is physically demanding enough for an able-bodied person. Imagine what it's like for a farmer with a severe disability, such as an amputation, paralysis, or a visual impairment.

Those images stirred Purdue University's Breaking Ground Resource Center to action. The result was *The Toolbox*, a resource manual for farmers with disabilities. First published 15 years ago, *The Toolbox* was believed to be the only such catalog for assistive technology for farmers.

"The third edition recently rolled off the presses, with many new and updated sections," said Paul Jones, manager of the Breaking New Ground Resource Center. The center is Purdue's outreach program for farmers with disabilities. There are about 550 different items featured in *The Toolbox*.

"You'll find such things as tractor lifts, hitching devices and powered gates," Jones said. "A lot of these are homemade devices. Fifteen or twenty percent are homemade products people submitted."

Topic areas include: Shops & Shop Tools, Trucks & Off-Road Vehicles, Outdoor Mobility, Lawn & Garden, Outdoor Recreation, and Safety & Health.

Commercially available items are listed with supplier contacts.

Both the 1986 and 1990 editions of *The Toolbox* sold out print runs of more than 1,000 copies each. The manual's market is substantial. More than a half million farmers and other

agricultural workers in the United States have physical disabilities that make it difficult to perform routine farm tasks. And each year, approximately 10,000 new cases of debilitating injuries or illnesses occur.

"In the back of *The Toolbox* we've put case studies of individuals who've risen above their disabilities," Jones said. "A lot of them have the spirit that they're not going to be beat. They have the attitude that if they can't do something one way, they'll find another."

A *Toolbox* preview can be downloaded at the cumbersome web address: pasture.ecn.purdue.edu/ABE/Extension/BGN/toolboxpreview.pdf.

The Toolbox sells for \$80, including shipping and handling and can be ordered by calling (800) 825-4264. The Resource Center has a number of other resources, a list of which you may request by calling the same number.

Connie Panzarino

The Information Center notes with deep regret the death of Connie Panzarino, author, activist, art therapist, friend of the Center, and contributor to *Disability Issues*.

Ms. Panzarino had a progressive neuromuscular disease and used a wheelchair. She was director of the Boston Self Help Center and sat on the boards of the Disability Law Center, the Project on Women and Disability, and the Boston Center for Independent Living. She also was on the editorial board of *Access Expressed* of Very Special Arts.

Ms. Panzarino's dynamism, insight, inspiration, and wise counsel will be greatly missed.

From Our Readers

Dis Ability

by Ernest Ben Dorantes

I have Dis ability
Dat most folks can't see,
For when Dey is lookin'
Dey can't quite see me.

For Dey be perceivin'
Dey knows what I am;
But Deir Doughts, Deceivin',
Can't quite know Dis man.

For Dough he seems helpless
He's quite able yet;
And Dough he looks useless,
Dere's more Dere to get.

Dis boy has a mind still
Dat's quick on De job;
And he can yet find skill
In his frame to lob

At De tasks before him-
No matter how hard-
For even his own self
He do not regard.

As matter of fact,
His way might be slow;
But power to act
Comes when gearin' is low.

So slow down De judgment
Upon what you sees;
For Dough oaks grows slowly,
Deir mighty of trees.

Just stop all Dat Dinkin'
Dat Dis one's washed up;
For soon you'll be blinkin'
As he passed you up.

You may contact the author at: ernest@forbetterorverse.org.

The editor is happy to consider short submissions from readers for possible publication in future editions of this newsletter.

Mail or e-mail. infoctr@gis.net.

How to Find What You Need

by Nancy C. Schock, President

The Information Center is not currently able to provide the type of Information Service it knows is greatly needed. Therefore, we are reprinting the following article from a previous edition in an effort to help information seekers and providers.

This issue's special message contains ideas that may be useful to you in seeking your own information.

When exploring possibilities for yourself or a loved one to participate fully in life's activities you need specialized information. People facing disability are often unsure of where to look for this information, or what questions to ask. Furthermore, they frequently do not realize that they can or should be seeking life enhancing information. The issues raised by disability affect so many aspects of life that the range of possible solutions together with the rapid changes being made today present a daunting prospect for people seeking useful answers.

My first suggestion is to start exploring early with an open mind. You will be surprised at what is available. You can obtain information from many sources, such as knowledgeable individuals, agencies, or organizations, printed materials, the Internet, or by attending meetings or conferences. At some point, in your search, you will benefit from consulting with people who have lived or are living with the same situation as yours in order to learn how they have managed. Their solutions may not be right for you, but

they will give you ideas of options and alternatives.

The subject categories into which the Center divides all information appear below. Seeing them may help you decide what issues to consider and how to organize the information you find so that it will be most useful to you.

Access/Accommodation
Communication
Disability /Disabling Conditions /
Chronic /Illness
Education
Employment
Equipment /Assistive
Technology
Finance /Entitlements
Health Care /Treatment
Housing
Human Relations
Information /Resources
Law / Rights
Personal Care/Basic Needs
Recreation
Transportation / Travel

If you need help deciding what questions to ask, you can think of situations or activities in your life that are affected by disability and how you would like them to change. Think positively, assume that there is an answer. You have only to find the answer which works for you. Remember no one person or one organization has all the answers. Persistence is the rule. Persistence!

Where to Look

Telephone Book

Your telephone book is, in fact, a resource, not just the white

pages but the special sections which list community and government services.

Human Services Yellow Pages

This special "telephone" book which lists human service agencies, private organizations, and other groups dedicated to meeting the special needs of people living with disability, should be available at your local library.

Government

All states and many cities have at least one office dedicated to the needs of people with disabilities. In Massachusetts these include the Massachusetts Office on Disability, Massachusetts Rehabilitation Commission, Massachusetts Commission for the Blind, Massachusetts Commission for the Deaf and Hard of Hearing, Massachusetts Commission on Mental Health, and others. Call any one of them and ask them to refer you to the resource you need.

Independent Living Centers (ILC)

ILC's are essentially self-help centers that are run and staffed by persons with disabilities. They offer some or all of the following services: attendant care, coordination of personal care attendants, transportation, counseling, information and referral, independent living skills training, and self-empowerment. Most important, you will find people who have faced and understand questions very much like those you are dealing with.

Hospitals and HMOs

Recently the health care organizations have begun to take a more active role in many more areas of health. Your local

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How to Find What You Need

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hospital or HMO is likely to have a great deal of information on disability, hot lines for information, "talk to a nurse" programs, and a wide range of support groups. Call your provider first and then call every health care provider in your area until you find programs and services that meet your needs.

Disability Specific Organizations

Most major disability related organizations focus on one disability, or perhaps several related disabilities. These national organizations, such as the Multiple Sclerosis Society, usually have local or state chapters which you can contact. They have publications, meetings, and conferences which can provide both resources and networking opportunities. While many concentrate on research and education, others provide direct services to individuals with "their" disability. Do not overlook this resource.

Work

Because of the passage of the federal Americans with Disabilities Act, most employers have assigned someone to be the ADA Compliance Officer. This person can answer many disability related questions and access or refer you to resources. If your, or a family member's disability is affecting your job, talk to your human resource office.

Library

Your library and the librarian are resources. They have books on disability, resource guides,

publications of disability organizations, and effective catalogs to help you find them. In addition, today, many can give you access to the Internet. Many libraries also offer services such a text readers, large print publications, books on tape, and captioned movies.

Schools

With new laws and growing awareness the school has become a disability resource. The school nurse, guidance and special education staff can offer information and referrals. Colleges have centers and programs for students with disabilities. You do not have to be a student or have a student in the school to seek their advice.

Internet

The Internet not only has a wealth of disability related information, it may have too much. If you search the Internet with the word "disability" it will take hours just to read the titles of the sites you will find. However, if you have a good browser and ask specific questions you can find unlimited useful resources. One of the nice things about the Internet today is the number of people who love to spend their time "surfing". Feel free to ask even a casual friend who is "into" the net to search for you, more likely than not they will be very happy to have a mission to justify the time they spend "on the net".

Support Groups

There are hundreds of support groups that focus on specific disabilities. They are made up of people just like you, persons with disabilities and their family members. They often have local meetings where people gather to share experiences and information. They can give you the

opportunity to ask questions and share solutions. You can find them through the disability-specific organization, the community events section of the newspaper, a local hospital, or the *Human Services Yellow Pages*.

Happy hunting!

Get Out and Enjoy

What to try something new in a supportive and fun environment? Need a little guidance or encouragement getting yourself immersed in the great out-of-doors? If you live in, or near, Massachusetts there is really no excuse.

For more than ten years, Outdoor Explorations has been using the outdoors to promote community-wide, inclusive activities for people of all abilities. Activities range from overnight kayaking, sailing and hiking adventures to one-day introductory sessions in kayaking or rock climbing to community service projects in urban green spaces.

Activities are scheduled between May and October. Experienced guides lead all the trips. Some activities are ASL interpreted. All equipment, meals, and transportation are included in the reasonable and affordable fees. (Some scholarships are even available.)

Outdoor Explorations is located at 98 Winchester Street, Medford, MA 02155. A catalog of trips, activities, and clinics may be obtained by writing to them or calling (781) 395-4999. You may also visit their web site at: www.outdoorex.org.

Childhood Asthma

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impaired growth of lung function followed by declining lung function in adulthood.

- Clinical allergies and sensitization towards inhaled allergens during childhood may persist into adulthood. Children raised in allergen-rich environments are especially at risk for adult asthma.

- Less than 25 percent of children with asthma will experience a symptom-free adulthood.

Asthma is a social problem.

- Asthma is more common in cities than in rural areas. Urban, low-income children are at a higher risk for developing asthma and for poor asthma management.

The increased number of asthma cases in inner-city environments is the result of a complex array of factors including low-income households with unsanitary housing conditions,

limited access to care due to insufficient insurance coverage, lack of family support, and little knowledge about asthma, its consequences and ways to control it.

Asthma is often poorly managed.

Effective control of childhood asthma depends on timely education and access to care and medication. There are two therapeutic strategies for effective control of disabling childhood asthma: *intervention* measures to stop acute symptoms, and *maintenance* measures to prevent symptoms from reoccurring. The child's guardians and school administrators play important roles in successful long term asthma management. These roles include: constant vigilance of environmental quality to prevent triggering episodes at home or school; assuring that the child takes maintenance medication and knows how to use his or her inhaler; recognizing when the child's control is worsening; and knowing when to give the child anti-inflammatory corticosteroids (which act slowly) so that urgent care is not needed. The parent also needs to take the child to his or her regularly

scheduled appointments with the clinician monitoring the child's condition.

Rehabilitation of Childhood Asthma.

Pulmonary rehabilitation programs include exercise training, patient education about asthma management strategies, breathing exercises, relaxation techniques and recreational activities. Rehabilitation can improve functional status in terms of physical endurance and cardiovascular fitness. Greater exercise tolerance, in turn, is related to greater perceived quality of life.

To obtain the complete Issue Brief on Disabling Childhood Asthma, contact the NRH Center for Health & Disability Research, Suite 400, 1016 16th Street, NW, Washington, DC 20036; or visit their website at www.nrhchdr.org.

Kroll, T., Neri, M.T. & Palsbo, S.E. (2001). "Disabling Childhood Asthma" Health & Disability Issue Brief. Washington DC: NRH Center for Health & Disability Research. April.

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Please send *Disability Issues* to:

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IMPORTANT: If you no longer read *Disability Issues*, please help us serve others. Write or call us to cancel this subscription.

Taxi !

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have accessible vehicles available for service 24 hours a day.

If an operator is unable to promptly dispatch an accessible cab when requested by a person in a wheelchair, they must contact other companies' dispatchers until an available cab is dispatched. It is not acceptable to make you call the other companies.

If a person using a wheelchair is on the street, that person may hail any cab and request to have an accessible cab dispatched for them. If you do not have access to a telephone to request a cab, you may ask a driver to call his dispatcher for you on his radio. Drivers are sometimes, understandably, unhappy about this provision and it certainly should not be abused.

As a last resort, if you are having trouble getting an accessible cab in Boston, you are invited to call the Hackney Carriage Unit of the Boston

Police at (617) 343-4475. They will help locate an accessible cab. You should also call them with complaints or even words of appreciation.

Vivienne S. Thomson Independent Living Center

Vivienne Thomson was one of the great assets of Massachusetts. A whirlwind in a wheelchair she advocated effectively not only for people with disabilities, but for all social services, minorities in general and Native Americans in specific. Many important advances in our state were made because Vivienne was persistent and hard to refuse. She was a role model for concerned citizenship.

In fitting remembrance to her what was originally the Minorities with Disabilities Advocacy Center (MDAC) in Jamaica Plain is now the Vivienne S. Thomson

Independent Living Center/MDAC. Located at 555 Amory Street, Jamaica Plain, MA 02130, it is a full service ILC serving the needs of people in the Jamaica Plain-Roslindale-West Roxbury area. In addition, the Thomson Center is prepared to lend assistance to individuals from any part of Massachusetts who find that being a member of a minority group impacts upon dealing with a disability.

The Center is active in organizing and sponsoring special programs and emphasizes a wide range of support groups including a Women's Focus Group. They take a particular interest in the 14-22 year age group and assuring these persons receive proper services. They offer information and assistance with transportation, education, housing and employment.

The Thomson Center will be moving to new and expanded quarters in April 2002.

You may get additional information by calling the Center at (617) 522-9840 (v & tdd).