

Disability Issues

Volume 27 • No. 4

Winter 2007



The Road to Diagnosis

By Meryl Perlson

Editor's note: In this article the author, a new member of our Disability Issues Editorial Board, describes her struggle to find an explanation for her child's disability.

It is widely accepted that the first three years of a child's development are critical, and early treatment of delays greatly improves outcomes. So, when my husband and I realized our four month old daughter, Noa, had missed some developmental milestones we went straight to our pediatrician. We were also concerned about some unusual physical traits she had — fleshy hands, a sacral dimple, a funny alignment of her toes. Like most parents, we were happy to accept the pediatrician's reassurance that the traits were normal variations and that our mellow daughter was developing at her own pace. It was the same scenario at the next few check-ups. But by the time she was 10 months old, when Noa had mild hypotonia (low muscle tone), a clumsy crawl and wasn't babbling, we were no longer reassured.

We learned that most pediatricians are developmental generalists. If your child has unexplained developmental delays, pediatricians board

Continued on page 5



PAUL KAHN: We

go back more than 30 years. What has changed for people with disabilities in that time and what hasn't changed?
COMMISSIONER CARR: I think the biggest change resides within us. I think we're battle-scarred and still surviving and living out in the community and living a life that perhaps we never thought we'd see when we were lying in our rooms at Wellington Hall back in the '70s, rooms that were probably smaller than a jail cell. I used to dream, but I don't know that I was capable of dreaming about sitting in the corner office at Wormwood Street. What changed fundamentally in me was my own self-confidence and self-esteem. Paul, I remember sitting in the hallway at Wellington Hall, talking with you about simple things like dating and relationships and things that people that don't have disabilities don't worry about so much. Having a family, owning a home, having a job, having a vehicle, having a peer group and friends — those are the things I cherish the most and see as huge changes for people with disabilities. Then, on the other hand, I'm really deeply concerned and upset and angry about what hasn't changed. We're still living

Charles Carr

Interviewed by Paul Kahn

Part 2

We continue our conversation conducted this fall with Charles Carr, Commissioner of the Massachusetts Rehabilitation Commission.

in poverty. We're still marginalized. We're still oppressed. We're still discriminated against. Most people are unemployed. Seventy percent of people with disabilities are still living on SSI and SSDI. That's pathetic. And we're 17 years post-ADA and 13 years post-Olmstead. To this day, we do not have an Olmstead Plan in place in this Commonwealth. That's an embarrassment. It's something I plan to push for. We still have icons of oppression like the Fernald School protected by the courts. The other thing that worries me is that none of us is doing a very good job building young leaders as we grow older. I think there's a huge vacuum between people in our age group and the twenty-somethings. That's troubling.

KAHN: What's kept us from making more progress?

CARR: We haven't yet gone to the next logical place, which is to address the issue of poverty and socioeconomic status. One of the primary reasons I took this job was to take on that issue. That's all about breaking down the barriers that keep us from getting jobs. I think a lot of it is our need to organize the grassroots campaign, as

Continued on page 2

Inside This Issue

The Road to Diagnosis.....	1	VA Helps Disabled Veterans Re-enter Work World	5
Charles Carr Interview - Part 2	1	Information Briefs	6 & 7
From the Editor.....	3		

opposed to what's traditionally happened, which is a top-down, VR model. That's necessary, but we need to become more active as a movement of people pushing the system and wanting and tasting and feeling the freedom that employment and money brings.

KAHN: Would you agree that part of the problem is the inadequacy of the PCA program? There are various efforts to help people get employed. On the other hand, those efforts are undermined because you can't get PCA hours that are related to employment needs. And the PCA pay rate is so low it's a constant struggle to get even minimal care.

CARR: I think we have to go back and remember the origin of the PCA program. The origin was you and me battling the system to shake free money to allow us to live independently. Back then, there were maybe 15 people using PCAs. Now, there are 15,000. It's a huge program. And we don't stop and think about the positives enough. But shame on us, because what we've done is allowed this program to get away from us. We've allowed it to come to a place where I don't feel that the mantle of the program is safe any longer, and that's consumer control. I worry that that integral piece that defines it from any other support system is eroding. I feel that us controlling our PCAs is more fragile than since I can recall. Part of that is, I think, the overwhelming explosion of the program and the different populations using PCAs, like elders and children and so on. That's all fine. But I think, as a community, we need to stop now and reel it back in. What I'm proposing is that MRC becomes the place where people with disabilities come through the front door — through a single portal — to access long-term care and to avail ourselves of community services and jobs. To that end, I would like very much to work with this administration to pull the PCA program into MRC and to manage it out of this

agency. Currently, it's housed at Elder Affairs and Medicaid. We've become so medicalized in the last seven or eight years. It's become a nightmare. It's time to simplify it and bring it back under our control — not to the exclusion of any population that currently benefits from it, but to safeguard it and keep it streamlined and effective. I'm trying really hard to convince this administration that MRC should be the place where it lives and grows.

KAHN: What other changes would you like to see to the PCA program?

CARR: The elephant in the room is capitation [spending based on a fixed amount per person]. It's a runaway program financially in the eyes of the bureaucrats. It's probably a 300 million dollar program right now. But we should be focusing on the benefits, rather than the cost. I will probably receive a lot of flack for this, but I don't personally believe that capitation equals death. I think that capitation is a way to control costs. If it's done properly, we'll have a great program. I wish the bureaucrats would come out and say, "In an effort to control costs, we want to capitate the program and we would like you users to help us figure out capitation methodology that makes sense." Whenever you ask users of a product or service to assist in improving it, 99 percent of the time you come away with an improved service or product. Let's stop lying to each other and start talk about what we need to do to make the program strong.

KAHN: What other new directions are you thinking about taking MRC in?

CARR: One of the ideas that I have is using government as a model employer. I would like to approach the Governor and ask him to write an executive order that makes the State of Massachusetts a model employer for people with disabilities, to put our money where our mouth is and say to the private sector, "We are serious about employing people with disabili-

ties. We would like you to follow our lead and do the same thing." That, to me, would be a tremendous accomplishment in my short tenure here at Mass. Rehab. As I also mentioned, I would like to bring more long-term care pieces into MRC, to flip the paradigm, so that MRC is no longer the "VR agency," but it's the "Community Services agency." Not to minimize work force and job development — that's key — but to make this the place where people with disabilities go. Some of these initiatives fall around the 1115 waiver.

KAHN: What is that?

CARR: It's a way to take Medicaid money through a demonstration and use it creatively to create programs for people with disabilities to live in the community without following the stringent rules of Medicaid. The other initiative that I'm really high on is pre-admission counseling, Chapter 211, which was the Equal Choice Bill. This is essentially a two-piece regulation. It allows money to follow the person from a nursing home into the community to purchase community services, but also, if the person is in an acute-care setting, prior to being discharged they are now entitled by law to have an advocate come in to explain to them what their community services are. Those are a couple of areas that I would like to see MRC play a huge role in during the next two or three years.

KAHN: For a long time, you've been an outspoken advocate for people with disabilities. How are you going to balance advocacy with being part of the establishment?

CARR: I want to tell you a great story that inspired me when I was younger. The independent living movement draws its direction from the civil rights movement. There was a young litigator named Thurgood Marshall who litigated *Brown vs. the Board of Education*. He rose to become one of the finest Supreme Court justices that this coun-

Continued on page 4

Disability Issues is a joint publication of the Medicaid and Comprehensive Employment Opportunities Infrastructure Grant (MI-CEO) located at the University of Massachusetts Medical School Center for Health Policy & Research, and Spaulding Rehabilitation Hospital. The MI-CEO Grant is funded by the Centers for Medicare and Medicaid Services and administered by UMASS Medical School Center for Health Policy and Research; UMASS Boston Institute for Community Inclusion; and the Executive Office of Health and Human Services (CMS CFDA #93-768). For more information visit www.MI-CEO.org.

Feel free to reprint articles. When doing so, please credit Disability Issues (Vol., No. and Date). For articles that appear under a byline or that will be altered in any way, please obtain permissions from the editor. Any inclusion or exclusion of a particular entity, product or service in this newsletter does not constitute endorsement or opposition.

Editor: Paul Kahn

Editorial Board:

Bill Henning
Raymond E. Glazier
Linda Long-Bellil
Susan Murray
Sandy Novack
J. Archer O'Reilly III
Meryl Perlson
Nancy Schock
John Solomon
Carolyn Thompson
Doe West

Contributors:
Sandy Novack
Meryl Perlson



From the Editor

In this edition of *Disability Issues* we conclude our interview with Charles Carr, Commissioner of the Massachusetts Rehabilitation Commission. One of the points Carr makes is that the disability community has not done an effective job at developing a new generation of young leaders.

I agree with him and share his concern. I'm an old-timer myself and know that people of my age, particularly people with disabilities, don't have as much energy as we once did to fight the same battles over and over for all the fundamental of a decent life — PCAs, affordable housing, accessible transportation, public accommodations, and access to health care, education and employment. But when I go to community events I tend to see the same aging faces in the front of the room.

Perhaps the reason is that young people with disabilities are taking advantage of the advances in civil rights that have already occurred and are simply living their lives with more freedom than we, the old guard, enjoyed. Perhaps they don't have the fire and the hunger that motivated us in the early days of the movement.

I frankly don't know. But indisputably there is more work to do, as other articles in this issue make clear — from the issues faced by returning disabled veterans to the travails of a family searching the medical world for an understanding of their child's condition.

In the future we hope to return to the issue of leadership development, and we welcome your insights on this topic. We also hope that any of you with knowledge of the real experiences of disabled veterans will comment about that.

Paul Kahn

Please Note: The article "*Support Groups: The What, the Why, and the How,*" which appeared in the Fall 2006 edition of *Disability Issues* (Volume 26, No. 3) was mistakenly attributed to J. Archer O'Reilly III. The original author was Linda Hillyer.

Subscribe

Disability Issues is available without charge to anyone who finds it useful and interesting. To request a print or Email subscription, please write to:
Center for Health Policy and Research
University of Massachusetts Medical School
222 Maple Avenue, Higgins Building
Shrewsbury, MA 01545;
call 508-856-7857/voice, or go to www.masschec.org.

Disability Issues is also available on tape and in large print. To receive either of these special formats, contact the Perkins Braille & Talking Book Library at 800-852-3133 or e-mail library@perkins.org.

To view Disability Issues on-line go to www.masschec.org or www.DisabilityExchange.org/newsletter.

try has ever known. When I was in my twenties I went down to Washington, and I took a trip over to Arlington National Cemetery. I went over to the area where the dignitaries were buried, and there was one single black stone. There were two words on it: "An Advocate." It was Thurgood Marshall's headstone. I came away from that experience, thinking about how it must have been for him to have been a fire-brand attorney, arguing for integration of people of color and then rising to the highest place in the land. I believe that in order to be effective within government you have to be an advocate. What I have to work on is the decorum of this office, loyalty to this governor. I believe that with a fair amount of self-censorship and some good people around me I won't have any difficulty being an advocate and a commissioner at the same time.

KAHN: What would you say about the issues that have already cropped up with this administration, like PCAs not getting a scheduled pay review?

CARR: I want to point out some positive things that this governor has done. One of the things I feel incredibly good about is his tenacity around the Fernald School issue; he continues to go back and tries to find some common ground between the families who want to keep the Fernald School open and the advocates on the outside who want the School to close. I think he's doing incredibly good things in that area. The fact that the PCA Workforce Council is in his Supplemental Appropriation and he's working to support that Workforce Council I think is a huge positive. Regarding the issue you're talking about, I challenge the union to step up and say, "We agree with the disability community that we don't feel it's appropriate for people with disabilities and PCAs to wait until we organize and we finally collectively bargain for a rate increase. There's a promise that's been broken and should be kept, and there should be an increase. What we as a union are able

to accomplish in six or eight months remains to be seen." I would ask the union to stand with us and lobby A&F to grant this interim pay raise to PCAs. This is small money, but it's necessary money.

KAHN: Your wife Karen works at MRC. Are you going to be her boss?

CARR: As part of my learning curve I realized early on that the state has very strict rules about ethics, and perception of a conflict is unacceptable. The negotiation around my coming into MRC included Karen's position, which is an incredibly important position, as Director of the Independent Living and Assistive Technology Programs. I didn't want my wife to fall on her sword on my behalf, because her passion is here at MRC with independent living. So, I believe there has been a nice balance worked out. She now is going to go to EOHHS. Half of her time will be spent on the assistive technology program that she grew here at MRC. The other part of her time will go to another area — the Governor's Community First Initiative. It will be looking at some of the things the administration is working on around community services. This leaves a phenomenal vacuum here at MRC. It's good for Karen and not so good for us, because we're losing the person who was the spirit behind the IL division.

KAHN: When I think of where we started, I'm incredibly impressed with all the things you've done to contribute to the movement.

CARR: It's stranger than fiction. I do remember when we were kids living in an institution, dreaming about just getting out. I've never stopped dreaming. I was able to make more progress, and as the movement made more progress my dreams became broader and more encompassing. I think all I'm dreaming about is to get us, as a movement, to a place where we're on a level playing field with everyone else. That's not too much to ask, but it takes a long way to get there!

KAHN: What I would like is to have things so that people like you and me and a lot of people with disabilities don't have to be faced with the question of just survival.

CARR: It is hard. We're getting older, and our sphere of influence is being challenged. I just go back to the need for us to have a cadre of younger people who will be as resilient as we once were. The nature of bureaucracy is always to retrench, retrench, retrench. How many times can we fight the same battle around PCA wages? Under Governor Romney, we lost prosthetics and eyeglasses and dental care. How many times do we need to come to the same conclusion that it doesn't make sense to keep beating us down to save a nickel or a dime! This governor has a vision of hope. During my brief tenure here I want to get a lot of stuff done that hopefully can't be unraveled.

KAHN: You don't see yourself staying 30 years?

CARR: No, I don't see myself living 30 more years. I'd be eighty-something. I see this as a three to five year opportunity. I very much like the private sector. I love where I came from. I see this as an opportunity I'm compelled to take advantage of. But I don't know how much I can take. It's hard. Even from the seemingly lofty position of a commissioner, the inertia of status quo is phenomenal. It's staggering. So we just keep punching away. That's why my secret — my 11 herbs and spices, if you will — is not really a secret at all. It's all about the disability constituency, pushing in tandem with me and this team here. Because finally, sitting here in this room is a person who came from an institution and rose to this position who won't ever forget where he was and how that feels. I'm just a lost PCA away from a nursing home, just like you. One system falls apart, and I'm not sitting in this office.

certified in developmental-behavioral or neuro-developmental pediatrics are the experts who can save you months of uncertainty. We were lucky our practice included such a pediatrician. Children's Hospital's Developmental Medicine Center also has several on staff.

We also sought help from the state's Early Intervention program (EI). EI provides services to children under three who have developmental delays. Services are provided in your home or at your child's day care at little or no charge. By Noa's first birthday, she had bi-weekly sessions with therapists who also taught me how to help her between visits.

After evaluating Noa, our new pediatrician referred us to several specialists. All had huge waiting lists, a year long in the neurologist's case. I signed up for cancellation lists, checked weekly for openings, and traveled to satellite locations. Within months we ruled out allergies, hearing and anatomical problems. We even landed a last minute opening with the neurologist. He told us Noa had no unusual physical symptoms, but she did have a few behavioral characteristics of

an Autism Spectrum Disorder (ASD). He commended us for starting therapy early and urged us to increase it. Then he explained it was too early to diagnose and asked us to come back in six months. We found a neurologist specializing in autism and repeated this scenario twice over the next year.

Parents of children with special needs are constantly told they are the best experts on their children, and also their best advocates. As the ones who attend every appointment, it's up to us to manage the flow of information among practitioners. It's crucial to keep organized because the paperwork is staggering. I learned to bring a notebook of every report with me to each appointment and to keep a master list of every outcome and recommendation.

We had good private health insurance,

but issues arose. Our insurer (like most) wouldn't cover the additional therapies recommended by the neurologist because they were considered developmental, not medical, in nature.



The Perlson family: (left to right) Simon, Meryl, Jim and Noa

MassHealth's CommonHealth program covers children with disabilities, regardless of income level, and might have helped. But at that point Noa had not been diagnosed with a disability. Our expenses mounted.

An unexpected challenge was how alienated we felt having a toddler with delays. By 17 months Noa was at a nine

Continued on page 7

VA Helps Disabled Veterans Re-enter Work World

By Sandy Alissa Novack, MSW, MBA

Mel Tapper, PhD, LICSW is the OIF-OEF (Operation Iraqi Freedom-Operation Enduring Freedom) Program Manager for the Veterans Administration (VA) Boston Healthcare System. Recently I had the opportunity to learn from him about some of the 650,000-700,000 military men and women who have come back from duty at this point and are now veterans. This number does not include those who have returned but remain in the military. Dr. Tapper estimates that only about 250,000 people have come in to the VA for services; with an all volunteer military and slightly more than half having been in the Reserves and National Guard, these veterans are older and have already been employed.

So, many prefer to return to their former health insurance and former jobs.

NOVACK: How is a disability defined at the VA for employment purposes?

TAPPER: According to the VA rating system, a disability of 20% or greater could qualify a person for the vocational rehabilitation benefit, allowing a veteran to be retrained. Another factor is how the disability impacts a person's functioning. What percentage of a veteran's functioning has been affected by their disability, and what is the employability component? For example, a person may have lost their hearing, and yet they can do their job.

The three largest diagnostic categories are: Primary category—muscu-

lar-skeletal injuries, including joint issues. Second largest category—mental health, with two diagnoses being PTSD (post traumatic stress disorder) and alcohol abuse. Third largest—neuro-sensory, including hearing loss and tinnitus.

NOVACK: What are some of the issues involved with a job search for a veteran with a disability?

TAPPER: A veteran can be retrained in any area that makes sense. For example, a veteran presenting with severe arthritis can be allowed to go to a graduate school for a degree that accommodates the arthritis. The veteran is

Continued on page 8

Information Briefs Information Briefs Information Briefs Information Briefs Information Briefs Information Briefs Information Briefs Information Briefs Information Briefs

PCAs Vote to Join Union

In November personal care attendants (PCAs) voted YES in support of joining 1199SEIU, the service employees union, by a margin of 94%. PCAs compensated via MassHealth and CommonHealth will be eligible to be in the union.

The vote was an expression of their need for better wages and benefits. Even though consumers and advocates have been working for PCA pay raises for years, wages are still too low, and there are no benefits. This year the state did not grant any pay raises for PCAs, despite intensive advocacy by consumers.

PCAs are meeting all over the state to get ready to negotiate with the PCA Quality Workforce Council and the state's Executive Office of Health and Human Services over their wages, health insurance, and paid time off. The timeline for bargaining depends on how long it takes to come to an agreement. No pay raises or benefits will take effect until a contract has been negotiated and approved by a majority of PCAs.

Transcripts of Candidates Forum on Disability Available

The transcript of A National Forum on Equality, Opportunity, and Access, the presidential candidates forum that took place in Manchester, NH in November, is now available on the AAPD website <http://www.aapd.com/News/election/peac2008.php>. The transcript is currently available in two large files — one of the morning hours and one of the afternoon hours.

The forum was hosted by the Granite State Independent Living Center and a New Hampshire coalition of disability organizations and sponsored by more than fifteen of the country's largest national disability organizations. Manchester Community Television televised the event, which featured live appearances by the presidential candidates and an audience of over 500 New Hampshire voters with disabilities, their families, and their friends. During the forum, each candidate had an opportunity to present his or her vision for the future of national disability policy.

New Resource for Parents Available

The HSC Foundation, in partnership with George Washington University's Graduate School of Education and Human Development, is offering a new resource for

parents of children who have been diagnosed with health or mental health care needs. The booklet entitled *Partnering with Your Child's School: A Guide for Parents* is available online and in hard copy in English and in Spanish. It is designed to help parents learn about available resources and to develop a partnership with their children's schools. The booklet's content has been reviewed and validated by groups of parents, youth, and educators and is produced in partnership with the Council for Exceptional Children and the National Association of State Directors of Special Education. For more information go to <http://www.hscfoundation.org/whatwedo/familysupports.php>.

Source: HSC Foundation

New Online Resource Founded

Skip's List is an online resource founded by Alfred H. "Skip" DeGraff with the mission of providing a world-class, online, user-friendly, apolitical, and free information exchange that serves, and is accessible to all people with disabilities, as well as their families and friends; that is abundant in consumerism but relatively free of commercialism.

DeGraff is a C 5/6 spinal cord injured quadriplegic who has used a motorized wheelchair and personal care assistance for about 40 years. In 1975, he founded and for 10 years was the director of the Department of Disability Services at Boston University. Next, he was the CEO of two independent living centers in Upstate New York. He was then the original designer and manufacturer of the Saratoga Cycle. He is also the author and publisher of the 512-page book, *Caregivers and Personal Assistants: How to Find, Hire, and Manage the People Who Help You (Or Your Loved One!)*. In 2006, he finished full-time studies to earn a doctorate in human rehabilitation and disability studies at the University of Colorado.

After using Craig's List, he decided a similar, interactive Web site would offer many communication benefits to the disability community. And that's how Skip's List was started. Craig's List is a simple concept, proven to be a powerful way to use the Internet. In essence, Craig's List provides two types of services — classified ads and threaded discussion forums. Today, 10 years after its establishment, Craig's List gets 10 million postings and 4 billion page views monthly. While Skip's List might never achieve such numbers, DeGraff envisions it being able to provide its users with very similar power and efficiency of communication and community.

New Web Site Markets to Disability Community

A new Web site Disaboom.com combines the social-networking features of Web sites like Facebook with information of interest to the disability community — medical news, career advice, dating resources and travel tips. Disaboom went live in October and hopes to attract more than a million visitors each month by the end of February and to double that over the next year. Founder J. Glen House, a quadriplegic as a result of a skiing accident, and his investors took the company public in May, listing it on the Over the Counter Bulletin Board securities market. At the end of June the company listed assets of \$2.2 million. Among some advertisers who have already signed contracts with Disaboom are Netflix, Johnson & Johnson, Avis, Cricket Communications, and Ford Motor Company. “I don’t think mainstream advertisers realize the magnitude of the marketplace and how underserved it was,” said Howard Lieber, vice president for sales at Disaboom. People with mobility challenges are active consumers. A 2005 Harris Interactive study commissioned by Open Doors found that 69 percent of adults with disabilities — more than 21 million people — had traveled for either business or pleasure at least once in the preceding two years.

In that same period, more than half had stayed in hotels, while 31 percent had booked at least one flight and 20 percent had rented a car. More than 75 percent of people with disabilities dine out at least once a week.

MassHealth CommonHealth Outreach Campaign

The Medicaid Infrastructure and Comprehensive Opportunities Grant (MI-CEO) in collaboration with MassHealth has developed an outreach campaign to inform people with disabilities about health insurance options for those who are working. A brochure will be mailed to over 35,000 MassHealth members with disabilities, informing them of employment services and supports as well as how to get benefits information related to employment. The brochure also profiles two people who have successfully become employed. To obtain a copy in either English or Spanish e-mail chcampaign@umassmed.edu. More information about employment and health insurance can be found at www.masschec.org.

Road to Diagnosis - Continued from page 5

month old speech level, crawling awkwardly and sometimes hard to engage. People commented. It was difficult to be around parents of typically developing same-aged kids. Yet, because we weren’t emotionally ready to accept that she had a permanent disorder, we ignored resources for parents of kids with special needs. In retrospect, I wish we had reached out earlier, as the North Shore ARC, Autism Support Center, Ladders Program (for autism) and Family Ties were ultimately incredibly helpful.

Noa had her fourth neurologist visit at 27 months old. She had made great progress but still had motor delays and almost no speech. The neurologist said Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) is a diagnosis given to kids whose symptoms resemble but don’t meet the ASD criteria. I asked whether Noa’s physical traits, which had been dismissed before as irrelevant, were important. She said it was worth looking into further, gave Noa a PDD-NOS diagnosis, and referred us to a geneticist.

Though I had previously searched the internet for clues to Noa’s diagnosis, I was curious about this new genetic angle. With the geneticist appointment a month away, I decided to Google again, this time including Noa’s delays and physical traits: Fleshy hands; Sacral dimple; 2,3, Syndactyly (the funny little toes); Language delay; Motor delay; Enter.

And that was how we learned Noa had 22q13.3 Deletion Syndrome (aka Phelan McDermid Syndrome). A tiny piece of her 22nd chromosome is missing. The geneticist later told us she is one of 350 known cases, most of whom are children under ten (the chromosomal test was developed fairly recently). A third receive wrong diagnoses before being correctly diagnosed. Characteristics of the disorder include severely delayed or absent speech, motor delays, autistic behaviors and significant cognitive delays. Many of these kids also share Noa’s physical traits.

The diagnosis has brought us many things, including grieving, knowledge and support. It hasn’t answered all our questions. The rarity of the syndrome makes a prognosis impossible. But we have a starting point. And we have a sweet, happy four year old daughter who is already learning more than we ever imagined.

Meryl Perlson is a freelance writer and communications consultant. She is also a full time mom to Simon, age nine, and Noa, age four.

also given a stipend (person is compensated for the disability).

The VA is ahead of the curve with tele-health and tele-medicine (which involves assessing peoples' health from a distance), so that no matter where veterans are, such as rural areas, they can access health care. Still, a farmer with a leg injury faces the life decision of whether he should be closer to a city for a job.

Mental health diagnoses can be stigmatizing. For mental health matters, an issue to be considered is what can a person tolerate for stress? An individual presenting with PTSD could find himself always questioned as to whether he can work. But, it is the capacity to function, and not just the diagnosis, that matters. Just because you have a disability does not mean you cannot work. Most veterans with a 0-50% disability rating are working.

Sometimes people have silent disabilities; they have no obvious disability such as from a bullet wound but do

have trouble relating to others, trouble taking orders, or anger. "Compensated work therapy" allows people to be retrained in a supervised environment. They get at least minimum wage. There is a strong focus on homeless veterans.

There is a population of very young people right out of high school, with no real job skills except what they picked up in the military (being on-time for work, etc.). They have no history of employment. Such a person with a disability could be asked if they want to go back to school. Types of jobs (not a fast food job sweeping floors) are considered.

National Guard and Reservists with disabilities need to perhaps be retrained when they cannot go back to a previous job.

NOVACK: Are there reasons for a veteran with a disability to work with the VA versus the Massachusetts Rehabilitation Commission?

TAPPER: In Boston, the VA has a strong relationship with the State

Division of Employment and Training. We do careful assessments of veterans and may then refer them for further education and voc-rehab. The VA has strong links to the community, including JobNet and One-Stop Career Centers. Veterans with disabilities could go through the Massachusetts Rehabilitation Commission, but it makes sense for many reasons of accessibility and comprehensiveness to stay within the VA system for a continuum of care. The VA moves people along to get more responsible jobs; the VA can help veterans get more hours of work; the VA counselors maintain a list of employers; and the VA has a job finder on staff to connect with employers.



Disability Issues

Center for Health Policy and Research
University of Massachusetts Medical School
Higgins Building
222 Maple Avenue
Shrewsbury, MA 01545

Nonprofit Org
U.S. Postage
PAID
Worcester, MA
Permit No. 176