Information and Services for
Families and Professionals
From
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CRC Continuum

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Serving the Needs of Individuals with Disabilities and Those Who Care for Them

- Case Management
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- Diagnostic and Evaluation Services
- Section 504 Plans
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- Continuum of Care Plan
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- Special Needs Research
- Disability Management
- Cost of Care Assessment
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- Advocacy at Individualized Education Plan Meetings
- Vocational Evaluations and Job Placement Assistance

We Serve As

- Guardian
- Trustee
- Medicare Set-Aside Administrator

IN THIS ISSUE

Stepping Up to the Challenge

The approaches we use to meet the needs of unique populations

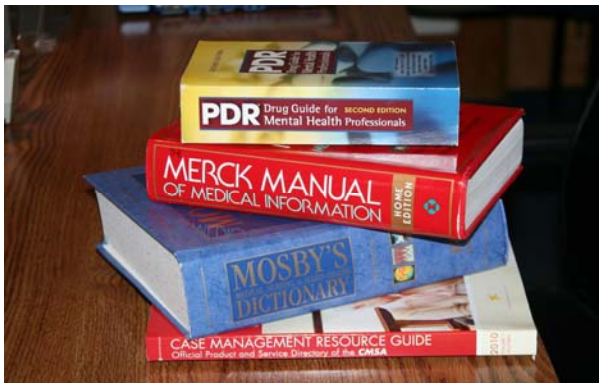
Zarahi Nunez, M.P.H.

As a rehabilitative consulting organization, we strive to be able to help anyone who approaches us for assistance in meeting their medical, therapeutic, or vocational needs. Whether it's being able to recommend appropriate suitable day program, arranging an appropriate summer camp experience, or suggesting modifications to make someone's home feel more like his own while insuring wheelchair accessibility, our goal is to be capable of presenting the best options available to maximally improve someone's overall medical condition, functionality, and independence.

To accomplish this, we must be very familiar with the unique challenges faced by individuals with different disabilities or conditions. All of our professionals therefore, dedicate themselves to pursuing any opportunities for educational development and for learning how to use different methods that are available for acquiring scientifically sound information. Doing all of this allows us to familiarize ourselves with the unique challenges faced by individuals with different disabilities or conditions.

With the technological advances that have been made in the past few decades, we now have all types of information at our disposal almost instantly, and CRC professionals are taking advantage of this. We can proudly say that we are able to provide assistance to individuals from multiple populations, from those with spinal cord injuries, to children with severe psychiatric conditions, to individuals who have suffered traumatic brain injuries, as well other populations, whose needs, challenges, and prognoses can vary greatly from each other.

CRC professionals use various means to seek out data, statistics, treatment guidelines, and currently accepted standards of practice for our clients. We read professional journals and publications which present the latest studies that have been completed, their results, and the implications of their findings. We subscribe to many publications such as Professional Case Management and the Journal of Life Care Planning in order to have them on hand at all times. If the information we need is not available in the journals to which we subscribe, we try to search through internet databases for articles published in other professional journals and publications and obtain or purchase the works we find most relevant. Examples of databases we search through are PubMed, which contains peer-reviewed primary research reports on life sciences and is maintained by the National Institutes of Health (1) and LexisNexis, which provides government, news, business and legal information (2).



As part of our dedication to ongoing educational development, CRC's professionals attend numerous functions throughout the year such as workshops on psychopharmacology, multi-organ transplants, brachial plexus injuries in newborns, and current trends in disease management.

There have been special cases where we have used unique approaches to learn more about a disability or condition so we could help our clients. An example of this is the help we provided to clients with a rare condition called Nephrogenic Systemic Fibrosis (NSF). This condition causes thickening of the skin on the hands, arms, torso, legs, and feet which can lead to contractures that cause an individual to be unable to move their body parts. Systemic involvement means that organs and body systems can also be affected which can lead to complications with existing health conditions. Because of its rarity, helping these clients depended on our ability to become acquainted with the condition and to finding out the best treatment methods available. CRC professionals spoke with leading physicians who provide services to NSF patients around the country, visited the NSF patient registry, (a website dedicated to gathering data, news, trends, and developments), and participated in a support group to communicate with patients and family members about their treatments, complications, and experiences. Professional medical journals were reviewed every few months for the latest research findings. Ultimately, we were able to familiarize ourselves with NSF so that we could best approach the needs of our clients.

Another population with unique issues is children who have reactive attachment disorder (RAD). Often the result of severe traumatic experiences, maltreatment, or abuse, children with RAD lack the ability to develop and maintain relationships with others, and therefore can demonstrate problems with manipulation, lying, cheating, stealing, aggressiveness, or violence. CRC staff members spoke to professionals who specialize in treating children with RAD who helped with learning about prognoses and treatments, and who assisted in identifying facilities suitable for children who required more intensive and comprehensive care. Our professionals even visited some of these facilities to observe their practices, methods, and services offered. They also maintained contact with clients' families to learn about their experiences with different facilities, schools, services, and doctors and to find out how their children were doing during and after treatment.

CRC can also perform special needs research to provide clients with information about a disability, condition, treatment, or service. In the past, we sought information regarding the most current treatments, approaches, and prognoses available for an elderly person diagnosed with multiple myeloma; we also researched to find out the latest and most effective treatments for Methycillin-Resistant Staphylococcus Aureas (MRSA) infections in individuals receiving peritoneal dialysis treatments. Our clients reviewed the information we presented to them to better familiarize themselves with their conditions, or to become better advocates for their health. They shared it with their families to increase everyone's understanding and knowledge of their family member's condition and they also shared it with their doctors to facilitate conversations about their diagnoses, courses of treatments available, and their prognoses.

One of the most significant ways that some of our professionals have been able to help others is through the use of their personal experiences. Knowing first-hand the needs and challenges faced by a particular group of people can provide priceless insight. In an article titled "A Personal Perspective on Catastrophic Case Management," our own Cynthia Kovacs has written about how her experiences as a case manager who is also a person with quadriplegia have helped her to help others. (See an excerpt from this article on page 4). Some of our professionals benefit a great deal from experiences with their own loved ones who have faced catastrophic injuries or who live with a disability. There is also so much that we learn from our clients, who provide us with first hand knowledge and

invaluable perspective all the time about the issues they face on a daily basis.

We now have so many different ways that we can obtain information, whether it's speaking to our clients, searching through databases, finding leading professionals in their respective fields with which to consult, or visiting facilities to observe their services first-hand. Taking advantage of all of these resources and using our own experiences gives us the best chance of gathering all the information we could need to make the best, most useful, and most efficient decisions possible for our clients. It also gives us the ability to try to lend our support to any population that requests our services. As techniques for acquiring information grow and change, we will continue to adapt to these changes, and will eagerly adopt the newest and most advantageous methods of carrying out our work, so that it can continue to remain valuable to the individuals and families to which we provide assistance.

References

1. "PubMed home." National Center for Biotechnology Information. N.p., n.d. Web. 29 June 2010. <http://www.ncbi.nlm.nih.gov/pubmed>.

2. "LexisNexis Academic and Library Solutions." Academic & Library Solutions LexisNexis. N.p., n.d. Web. 29 June 2010. <http://academic.lexisnexis.com/college-university-libraries.aspx>.

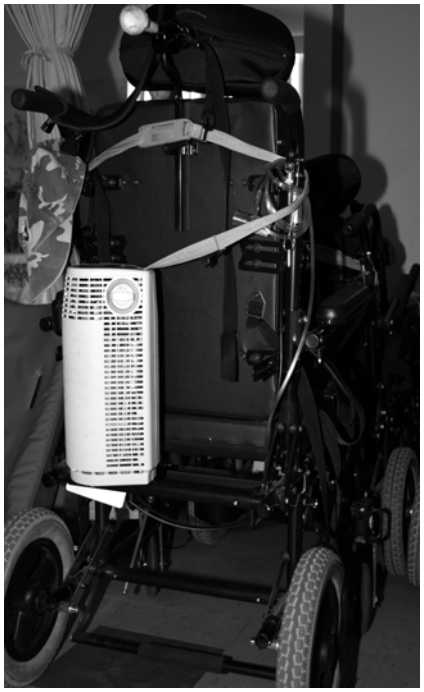
Sound Off….

Darlene Carruthers, M.Ed., CRC, CDMS, CCM, QRP, FIALCP

It always amazes me how much money we will spend on a vacation or a new car, but how little we invest in independence. CEO's, CFO's and the Board of Directors of various entities make decisions on a daily basis about how much (or how little) money to allocate towards rehabilitation, with seemingly little thought as to the negative consequences of cut-backs in patient care, but don't hesitate to pay themselves and their investors large sums of money in the way of salaries, bonus/perks and dividends. Rehabilitation, however, should not be thought of as an expense, but instead as a financial and social investment.

The word rehabilitation has its origins in the 1500's - rehabilitare, from re- "again" + habitare "make fit" or to restore; make able. All investors look for a return on their investment; the larger the return, the better the "investment." My question is how can we not see that investing time, energy and expertise into helping to restore health, function and independence to a person who was formerly able to care for themselves - is equally, if not more so, worthy of our resources?

Allocating resources for rehabilitation is currently not viewed as an investment in our fellow human beings and in society as a whole. This is evident when observing current rehabilitative practices, particularly length of stay (LOS) and mortality figures. The average length of stay in in-patient rehabilitation programs has been dropping, while mortality is increasing and rehospitalization with complications is rising. According to an article in JAMA, October 13, 2004—Vol 292, No. 14, the Median LOS decreased from 20 to 12 days (P_.001) from 1994 to 2001, while mortality at 80- to 180-day follow-up increased from less than 1% in 1994 to 4.7% in 2001. The National Spinal Cord Injury Statistical Center (NSCISC) began tracking the average length of inpatient rehabilitation stays of patients with spinal cord injury in 1974. At that time, the average length of inpatient rehabilitation stay for patients in Model SCI Centers was about 127.3 days. Over the next 20 years, NSCISC recorded a steady decline in that average. By 1986, the length of rehabilitation stay steadily dropped 36% to an average of 81.5 days. By 1994, the length of inpatient rehabilitation stay had fallen 57% from the 1974 level to an average of 54.6 days. In 2002, Medicare implemented a rehabilitation prospective payment system (PPS).



According to research published in "The performance of freestanding inpatient rehabilitation hospitals before and after the rehabilitation prospective payment system" by Jon M. Thompson and Michael J. McCue, January-March 2010, findings show that both nonprofit and for-profit freestanding inpatient rehabilitation hospitals reduced length of stay, increased discharges, and increased profitability during that time period. While hospital administrators advertise these statistics, implying that their programs are now more efficient, patients are actually being discharged too quickly, unable to care for themselves and often winding up right back in the hospital after growing sicker or developing complications, and in my opinion, ultimately costing more than it would have to stay a little longer in the rehabilitation unit. Patients are often discharged because policies frequently limit approvals for continued rehabilitation days by requiring patients to demonstrate a level of progress that is often too high to achieve. What the research does not show is whether quality and functional outcomes have been sacrificed to meet the requirements by Medicare and insurance companies and to keep profit levels stable or growing.

As consumers of services and purchasers of insurance, we need to speak up and out—we need to ask our insurance agents and company representatives specific questions regarding rehabilitative services coverage, both in-patient and out-patient. Paying a little more for better coverage is worth that one latte a week you might have to give up to afford it. If you have not needed these services in the past, you may not even think to look in your policy handbook to see what coverage is available. But rest assured, if the need arises for you or a member of your family, you will be glad you asked, you will be glad you have coverage and you too will recognize that investing time and effort in rehabilitation pays great dividends—that helping someone to put their life back together is certainly as important, if not more important, than a higher corporate profit margin or a bigger dividend for an investor….or that extra latte.

Excerpt from

A Personal Perspective on Catastrophic Case Management

Cynthia W. Kovacs, M.S.Ed., CRC, CDMS, CCM, QRP

My experiences as a person with a disability give me a rare perspective. I empathize with my clients and can offer hope for a fulfilling life. Those first years are so difficult for the person with the injury and their families. I always say that the family is also extremely affected by the injury and the dynamics of the family relationships are inevitably and indelibly altered. Adapting to and dealing with the physical and emotional aspects of the new reality can be overwhelming for everyone, to say the least.

Our company serves people nationwide, and most of my contact with our clients is over the phone. Many do not know that I have a spinal cord injury and use a wheelchair. I assess the person's needs and write up my plan of care and if the right moment presents itself, I might say something like, "Oh, did I mention that I'm a quadriplegic?"

After that, floodgates burst open and questions pour in. I let them know that they can ask me anything. I remember how hard it was to get answers when I was first hurt. Our relationship becomes more personal and I believe that the client benefits from having me as a confidant as well as a Case Manager.

The topics we discuss vary, but the most common ones are bladder and bowel management, stem cell research, driving, parenting, employment, personal care attendants, and assistive technology. My goal with all of my clients is the "3 E's" – empathize, educate and empower. I want to help them learn to help themselves. I provide them with local and state resources and direction on how to get through all the red tape that challenges even the most seasoned disability advocate.

When people have injuries that take away their independence, they often feel they have little to no control over their life. Physical assistance may be needed to accomplish the most basic activities of daily life. I use examples from my own life that demonstrate my ability to have control. Hiring your own personal care attendants and setting the schedule is one way. Going to school or getting a job is another way. Taking control of your own medical care - choosing your doctors, learning about your disability, gaining knowledge about nutrition - are all ways of feeling and being in control.

Case managers without disabilities can also help their clients successfully navigate through the process of adapting and regaining control of their lives. As case managers, we all have the responsibility of caring for our clients and using our skills to help them reach their goals. I believe that we all have life experiences that enable us to reach that end.

This article will be published in its entirety in *Professional Case Management* later this year.

We're On the Web!

We welcome you to explore our new website at **www.crcmiami.com**

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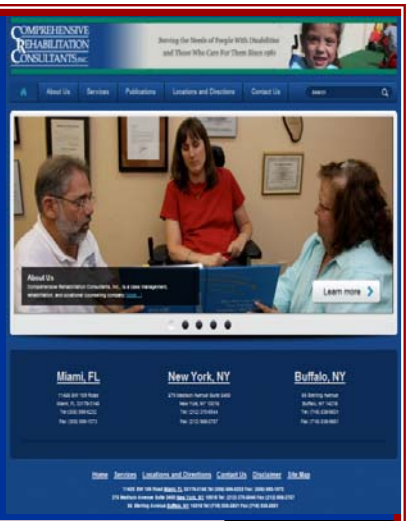
- Get directions and phone numbers to all of our offices
- Read descriptions of our services
- See ways to obtain books and articles written by CRC staff
- Read or download current and past issues of this newsletter
- Use our contact form to ask us a question or to send us your comments or suggestions and help us to continue to improve how we reach those we serve!



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