



Toward a Model System of Post-rehabilitative Health Care for Individuals with SCI

Extending the SCI Model Systems Concept
to Health Care in the Community

DEDICATION

Andrew I. Batavia, JD, MS
(June 15, 1957 - January 6, 2003)

And similarly situated individuals with SCI

Special Interest Group on SCI Model System Innovation

Members:

Gerben DeJong, PhD, Chair
National Rehabilitation Hospital
gerben.deJong@medstar.net

Charles Bombardier, PhD
University of Washington
chb@u.washington.edu

Jeanne Hoffman, PhD
University of Washington
jeanneh@u.washington.edu

Tony Chiodo, PhD
University of Michigan
tchiodo@med.umich.edu

Jean Hsieh, PhD
National Rehabilitation Hospital
Jean.Hsieh@Medstar.net

Alan Jette, PT, PhD
Boston University
ajette@bu.edu

Jane Wierbicky, RN
Boston University
Jane.Wierbicky@bmc.org

Yuying Chen, MD, PhD
University of Alabama
yychen@uab.edu

Anne Deutsch, PhD, RN
Rehabilitation Institute of Chicago
a-deutsch@northwestern.edu

Denise G. Tate, PhD
University of Michigan
dgtate@umich.edu

Michelle Meade, PhD
University of Michigan
mameade@med.umich.edu

Martin Forchheimer, MPP
University of Michigan
forchm@umich.edu

Greg Nemunaitis, MD
MetroHealth Rehabilitation Institute of Ohio
gnemunaitis@metrohealth.org

Mary Jo Roach, PhD
MetroHealth Rehabilitation Institute of Ohio
mroach@metrohealth.org

Michael L. Boninger, MD
University of Pittsburgh
Boninger@pitt.edu

Friends of the SIG:

Amie Jackson, MD
University of Alabama
Jacksona@uab.edu

Marcel Dijkers, PhD
Mt. Sinai School of Medicine
marcel.dijkers@mssm.edu

Kristjan Ragnarsson, MD
Mt. Sinai School of Medicine
kristjan.ragnarsson@mssm.edu

Allen Heinemann, PhD
Rehabilitation Institute of Chicago
a-heinemann@northwestern.edu

This report may be cited as follows:

Special Interest Group on SCI Model System Innovation (2010). *Toward a Model System of Post-rehabilitative Health Care for Individuals with SCI*. Washington, DC. National Rehabilitation Hospital: National Capital Spinal Cord Injury Model System (NCSCIMS). <http://www.ncscims.org/SCIModelSystemInnovationReport.pdf>

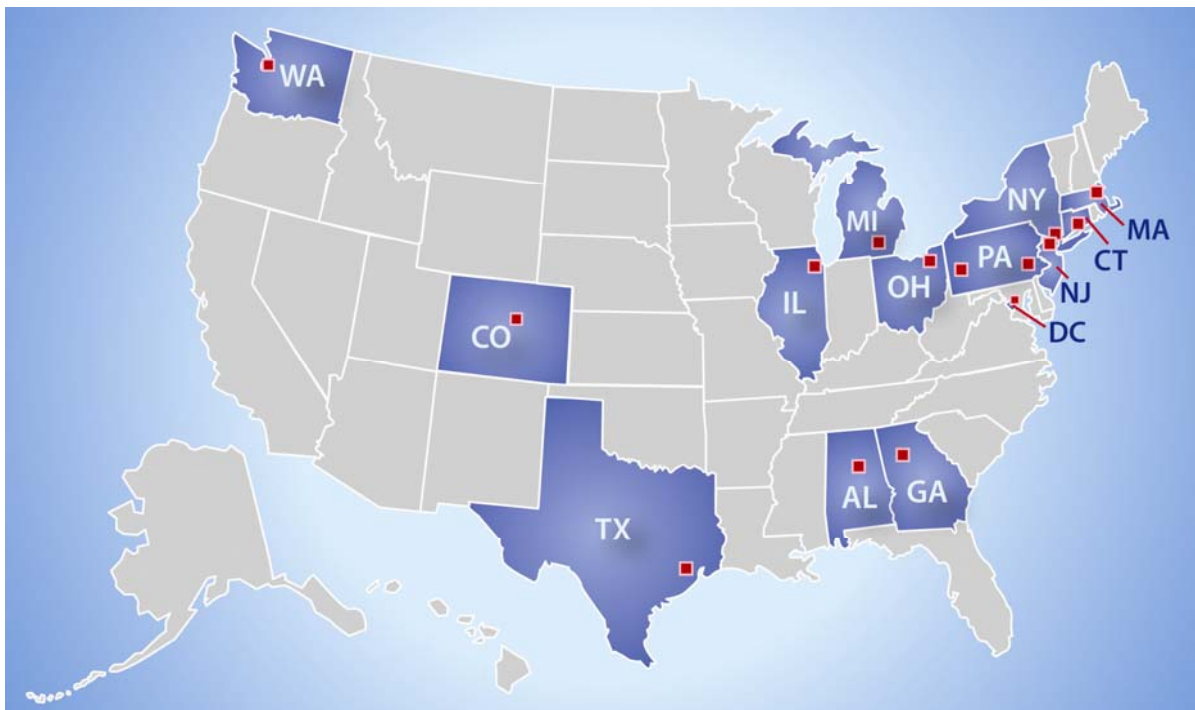
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**ABOUT THE
SPECIAL INTEREST GROUP ON
SCI MODEL SYSTEM INNOVATION**

The Special Interest Group (SIG) on SCI Model System Innovation consists of 15 individuals drawn from the leadership ranks of 8 of the 14 SCI model centers from across the nation. They have come together voluntarily to address what they view as one of the major unaddressed issues in SCI care. The SIG represents an interdisciplinary group of physicians, nurses, psychologists, researchers, and others with a long-standing commitment to the well-being of individuals with SCI. Collectively, they represent countless years of front-line experience in attempting to address the issues noted in this report.

This work brings together more than 25 years of literature. Sadly, many of the major themes in this literature have not changed materially over time despite the advances in early SCI care. They recount over and over again the challenges that individuals with SCI face in meeting their ongoing health care needs. The challenges are made greater, not because of our failures in early SCI care, but also because of our successes in saving and extending lives. SIG members believe that addressing these long overdue issues is especially timely given the opportunities for innovation inherent in health care reform. This report urges all stakeholders to double their commitment to solving these vexing but solvable challenges.

ABOUT THE SCI MODEL SYSTEMS PROGRAM



The Model Spinal Cord Injury (SCI) System program, sponsored by the [National Institute on Disability and Rehabilitation Research](#) (NIDRR), Office of Special Education and Rehabilitative Services, U.S. Department of Education, supports innovative projects and research in the delivery, demonstration, and evaluation of medical, rehabilitation, vocational and other services to meet the needs of individuals with SCI.

NIDRR awards Model SCI System grants to institutions that are national leaders in medical research and patient care and provide the highest level of comprehensive specialty services, from the point of injury through rehabilitation and re-entry into full community life.

Each SCI Model System contributes to the national SCI database, participates in independent and collaborative research, and provides information and resources to individuals with SCI, their family and care givers, health care professionals and the general public.

Grants are awarded in five-year cycles. The current 2006-2011 cycle consists of 14 SCI Model System projects around the U.S. as well as one [SCI data center](#) that directs the collection, management and analysis of an ongoing national SCI database.

Source: Model Systems Knowledge Translation Center, <http://msktc.washington.edu/sci/findms.asp#DC>

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LIST OF ABBREVIATIONS

ACO	accountable care organization
AHRQ	Agency for Healthcare Research and Quality
AT	assistive technology
CMI	Center for Medicare and Medicaid Innovation
CMS	Centers for Medicare & Medicaid Services
DEXA	dual energy X-ray absorptiometry
DME	durable medical equipment
ER	emergency room
FIM	Functional Independence Measure
MS	multiple sclerosis
NIDRR	National Institute on Disability and Rehabilitation Research
PACE	Program for all-inclusive Care for the Elderly
PHO	physician-hospital organization
PM&R	physical medicine and rehabilitation
PPACA	Patient Protection and Affordable Care Act
PTSD	post-traumatic stress disorder
SCI	spinal cord injury
SIG	special interest group
TBI	traumatic brain injury
UTI	urinary tract infection

SUMMARY OF RECOMMENDATIONS

An enduring issue for individuals with spinal injuries is how they can best meet their ongoing health care needs once they leave the protective cover of the rehabilitation center. The health care system is replete with features that undermine the ability of the individual to meet these needs in a timely and cost effective manner. The Special Interest Group (SIG) on SCI Model System Innovation believes that SCI model systems program is singularly well positioned to start addressing this unmet need. We make four recommendations:

1. The SCI model system concept should be extended to address the ongoing post-rehabilitative health care needs of individuals with SCI. In other words, future SCI model system grantees need to demonstrate not only how they will integrate acute and rehabilitative care but also they will integrate such care with post-discharge health care rendered in the community.
2. The SCI model systems program develop and pilot a “Form 3” that will document more systematically the health care encounters (e.g., rehospitalizations, ER visits, physician office visits, therapy visits) and other health-related experiences after discharge from rehabilitation.
3. The SCI model systems program fund a multi-site study or demonstration project to test one or more approaches to address the ongoing health care needs of individuals with SCI.
4. NIDRR enter into one or more interagency agreements that will enable NIDRR to use health care reform funding to support and administer innovative pilot and demonstration projects aimed at individuals with disabilities such as those with SCI.

Health care reform makes these recommendations especially timely. We are entering potentially one of the most innovative periods in American health care because of the health care reform law’s call for an extended period of piloting and testing new ideas in health care delivery and finance. Many of the law’s provisions are aimed at high-cost conditions, sub-populations, and episodes of care—the 20% or fewer that account for 80% of the cost. The law seeks to enhance the quality of care while simultaneously “bending the cost curve.” The law relies on the ingenuity of providers, consumers, health plans, and other stakeholders to develop new patient care models.

We believe that this is a rare moment for spinal injury care and it should be seized by all its stakeholders especially those in the SCI model systems program who are in the vanguard of improving SCI care across the continuum.

**Special Interest Group on SCI Model System Innovation
June 2010**

DEDICATION

Andrew I. Batavia, JD, MS
June 15, 1957 - January 6, 2003

And all similarly situated individuals with SCI

We dedicate this report to Andrew (“Drew”) Batavia whose life with spinal injury (C2/C3) encountered many of the issues presented in this report—both as a user of health services and as a scholar and researcher of health service issues. His life ended prematurely, in part, because the health system failed him, not out of ill intent, but because of reasons described in this report.

As a user of health services, Drew frequently encountered barriers in obtaining the services he needed. He was ever vigilant about his health and fully understood the narrow fault line that separated him from living independently and productively from losing control over his health and well-being, and facing even death itself. Obtaining timely and appropriate health services was essential not only to his health but his very survival.

Compared to many with SCI, Drew had many advantages in coping with the health system. His parents’ advocacy and latter his wife Cheryl’s care giving skills gave Drew the margin he needed to develop his own intellectual skills in law (Harvard Law, JD ’82) and health services research (Stanford University, MS ’84) that in turn gave him an important margin with which to make the most of his all-too-short life. These skills gave him the tools with which he could advocate for his own needs in the health care system. And yet, in the end, whatever advantages Drew had were not enough. We dedicate this report to Drew in part because we believe that no one should have to develop such a formidable armamentarium in coping with the health care system.

As a scholar and researcher, Drew wrote earnestly about the issues that motivate this report. No fewer than a dozen of the 40 papers he wrote on health care are cited in this report. His writings were both highly analytical and sometimes personal when he recounted his own health care experiences.

I had the privilege of knowing Drew as a friend and as a colleague during one of his most prolific phases in writing about health care, namely his four years with the National Rehabilitation Hospital’s Research Center (1986-90) before Drew became a White House Fellow. Our politics were very different but our collaboration always ended up at a place better than from which either of us had started. I will always remember this period as one of the more productive collaborations in my own professional life.

Implementing the recommendations of this report will, in many ways, fulfill the vision Drew had for how our health care system could better meet the needs of individuals with disabilities such as those with spinal injury. Although his research and writings are now 10, 20, and more years in the past, they remain as current today as they were then. Thus, this report is dedicated not only to Drew, but to all those similarly situated who cope not only with the demands of their own impairment but also with the challenges of today’s deeply flawed health care system.

Gerben DeJong, PhD, Chair
SIG on SCI Model System Innovation

For more on Drew Batavia’s life, see Appendix for an excerpt from THE LANCET • Vol 362 • November 1, 2003

FOREWORD

This report addresses long-standing issues related to the ongoing health care needs of individuals with spinal cord injuries (SCI). It argues that the SCI model systems program needs to move on to the next stage of its development. What makes it a model program is its search for innovation. In the past, it has been innovative in integrating the acute and rehabilitative needs of individuals with SCI. It now needs to bring innovation to their ongoing health care needs.

It has always been understood that the SCI model systems program should be more than a mere collection of regional centers. To that end, the SCI model systems program, from its inception, developed a national database to help discern larger trends in the etiology, management, and outcomes of SCI. Only recently, however, has the model systems program also become a platform for larger more highly powered, multi-center studies to answer questions that heretofore could not be answered by individual centers.

The SCI model systems program needs to build on this legacy of innovation if it is to remain vibrant and relevant to the needs of individuals with SCI especially as they live longer and need various types of health services. Yet, one of the more vulnerable periods in a person's life with SCI remains the early post-rehabilitative period when family and community supports, especially one's access to health care, are not yet fully in place and when an individual with SCI may not yet be fully aware of his or her susceptibility to various secondary conditions. This report calls for a stronger bridge from rehabilitative care to one's health care future.

Although the report is aimed in large part at the National Institute on Disability and Rehabilitation Research (NIDRR) and its SCI stakeholders, it is also relevant to other federal agencies and stakeholders particularly the Centers for Medicare and Medicaid Services (CMS) and the Agency for Healthcare Research & Quality (AHRQ) both of which have major responsibilities for the implementation of the recently enacted health care reform law (PL 11-148). The law, for example, calls for the development and testing of new patient care models that are very much in keeping with the direction suggested by this report.

The recommendations of this report and many of its observations about the health service needs of individuals with SCI also generalize in many ways, although not entirely, to the health service needs of other individuals with disabilities. We would be remiss to consider these issues as solely SCI issues. In many ways, SCI has served as a 'model', albeit an imperfect one, for how we can better address the needs of other populations with disabling conditions. We believe that an investment in enhancing the health care needs of this population will better prepare the nation to better address the needs of all individuals with disabilities.

Special Interest Group on SCI Model System Innovation
June 2010

TOWARD A MODEL SYSTEM OF POST-REHABILITATIVE HEALTH CARE FOR INDIVIDUALS WITH SCI

Access to timely and appropriate health care is vital to the health and wellbeing of individuals with spinal cord injury (SCI). Individuals with SCI use a disproportionate amount of health services and dollars compared to those without a disability or chronic health condition.¹⁻⁸ Despite their higher rates of utilization, individuals with SCI are more likely to have problems accessing the right kinds of health services they need when they need it.^{6, 8-12} This is particularly problematic for individuals with SCI because of their risks for deteriorating health, onset of secondary conditions, and loss of functional independence.^{13, 14}

This report outlines the scope of the challenge that individuals with SCI face when attempting to acquire the health services they need in a timely and effective manner. It documents potential solutions and identifies ways in which the existing SCI Model Systems concept can be extended to better meet the ongoing post-rehabilitation health care needs of individuals with SCI.

The SCI model systems, sponsored by the Department of Education, National Institute on Disability and Rehabilitation Research (NIDRR), had its origins in the 1970s to improve rehabilitation care for individuals with SCI who then were surviving at increasing rates. Today's challenges are different. Individuals with SCI live longer and face new health care challenges that accompany increasing longevity but neither our SCI Model Systems of care nor our larger health system fully reflect these challenges. We believe that the recently enacted health care reform legislation provides several opportunities for improving health care delivery for individuals with SCI and that the SCI Model Systems should embrace these opportunities.

Taking into Account SCI Natural History and Increasing Longevity

To serve individuals with SCI effectively, the existing health care system needs to take into account the natural history of SCI, and the risks for secondary conditions that individuals with SCI face especially as they live longer and experience many of the same chronic health conditions faced by others.^{5, 8, 15}

Increased health needs and risks for secondary conditions begin at the time of injury for individuals with SCI and continue for the remainder their lives. There is considerable research on the health needs and factors associated with, or contributing to, the risk of secondary conditions. Research indicates that the onset of secondary conditions can significantly impact an individual's health, quality of life, ability to return to productive activity, and life expectancy.^{16, 17}

Autonomic dysreflexia, for example, is a known complication of SCI, both in acute and chronic SCI, and can lead to a hypertensive emergency if not treated quickly.¹⁸⁻²⁰ Ready access to primary care can help arrest dysreflexia and prevent the potential complications of elevated blood pressure including cerebral hemorrhage and thus avert the use of emergency room care and hospitalization. Likewise, heterotopic ossification is an irreversible complication that can cause joint contractures that significantly interfere with function but it can be prevented through timely primary care management.²¹ Pressure ulcer risk is also high, both in the acute and chronic phases of spinal injury and increases over time post injury.²² Despite practice guidelines, improved seating, and other strategies to prevent the pressure ulcers, they continue to be a frequent and costly secondary condition.^{17, 23-33} Individuals with SCI can also develop difficulties due to pain,^{25, 34} neurogenic bowel and bladder,^{25, 35} and musculoskeletal issues such as osteoporosis, fractures, and overuse injuries.^{25, 36} Individuals with SCI have been found to be high users of outpatient physician visits and the majority of these visits are related to secondary conditions.^{37, 38} The onset of secondary conditions often precipitates an increased need for more help with activities of daily living.²⁸

Longer life expectancy is also associated with increased rates of obesity,³⁹ cardiovascular disease,⁴⁰ and sleep/respiratory disorders.⁴¹ Aging-related issues such as progressive pain, fatigue and weakness often result in loss of function.⁴²⁻⁴⁶ In short, individuals with SCI live longer but are at risk of acquiring new conditions, losing function, and becoming more dependent as they age.

Potential mental health needs of individuals with SCI should not be overlooked, especially conditions such as depression, substance abuse, and post-traumatic stress disorder, all of which can directly or indirectly contribute to other secondary conditions such as pressure ulcers that result from inactivity.⁴⁷

This litany of potential health challenges should not suggest that individuals with SCI are inherently unwell but does underscore that maintaining health and well-being requires additional vigilance *and* timely access to various types of health services that may not always be available as they should be.

Early SCI Management and Rehospitalization

Rehabilitation

Rehabilitation practice patterns in SCI have changed considerably over the last 35 years. Within the SCI Model Systems of care, for example, average length of stay in post-acute rehabilitation have declined from 115 days in 1973 to 36 days in 2005 (www.spinalcord.uab.edu).

Such a reduction can impact individuals with SCI and their families since many may not be prepared to make much-needed health behavior changes such as performing skin checks and pressure releases, managing bowel and bladder functions, and adhering to medication regimens.

Acute care stays preceding post-acute rehabilitation have shortened as well. Providers report that the number and severity of medical complications seen in individuals with SCI during inpatient rehabilitation have increased. These complications (e.g., pressure ulcers, pneumonia, and autonomic dysreflexia), require increased medical management while individuals are concurrently attempting to regain functional independence in ever shorter periods of time.²⁴ Thus, the initial short-term cost savings of early discharge from both acute and rehabilitative care may place patients at higher risk of increased rehospitalizations and thus contribute to higher long-term costs of SCI management.^{23, 26}

Rehospitalization

Rates of rehospitalization range between 19% and 57% in the first year after initial rehabilitation, with somewhat lower rates in succeeding years.^{23, 48, 49} Onset of secondary conditions is the main reason for rehospitalization.⁵⁰⁻⁵³ Secondary conditions include respiratory (e.g., pneumonia), skin (e.g., pressure sores), genitourinary conditions (e.g., UTIs), and spinal surgery/repair.^{23, 25, 30, 48, 54, 55} A recent Canadian study⁴⁸ examining the health system factors associated with rehospitalization, found that 27.5% of individuals were rehospitalized in the first year after SCI. Study authors found no significant change in rates of rehospitalization over time, suggesting that, despite improvements in care overall for individuals with SCI, prevention or treatment of secondary conditions continues to lag. These findings, though from another country, suggest that there may be systemic problems in the manner in which health care systems address the ongoing health care needs of individuals with SCI.

Research using data from the SCI Model System suggests that diseases of the genitourinary system (including urinary tract infections) were the leading cause of rehospitalization followed by diseases of the respiratory system and the skin.²³ Lower motor FIM [functional independence measure] scores at inpatient rehabilitation discharge were associated with more readmissions.²³ Some research has also been conducted to examine possible modifiable behavioral factors that are associated with risk of rehospitalization.⁵⁶

Addressing Ongoing Health Care Needs

The SCI Model Systems program focuses mainly on the acute and rehabilitation phases of SCI and less on the ongoing health care needs of individuals with SCI. Yet the successes of the last

35 years present new challenges as individuals with SCI live longer and lead more active lives. At the risk of some oversimplification, the post-rehabilitation health challenges facing individuals with SCI fall into two very broad categories: (1) access to primary care and related health services and (2) issues related to health plan coverage and payment. These have been enduring issues that should not remain unaddressed.

Access to primary care and related health services

Primary care is where vital preventative health services are provided and where the continuity of health care begins. Not having timely access to primary care leaves the person with SCI vulnerable to deteriorating health that otherwise could be avoided or slowed.^{2, 5-11, 57-61} While persons with SCI do acquire vaccinations at the same rate as non-disabled persons, other preventive services, especially those that involve imaging equipment or require an exam table (i.e. mammography, DEXA, pap smears, and cancer screening), are less likely to be received.⁶² A common denominator among these problems is that the built environments for these services do not lend themselves to persons who use a wheelchair. For example, physician offices often lack height-adjustable exam tables, wheelchair ramps, and van-accessible parking. Rooms housing imaging machines are often too narrow, lack grab bars and height-adjustable imaging tables for easy transfer from chair.⁶³

Because SCI is a relatively rare condition, most primary care physicians are not likely to see a person with SCI very often, if ever, in their practices. Moreover, wheelchair users are sometimes seen as patients who require more time than a busy office practice usually allows.^{5, 9, 59, 64} As a result, many primary care physicians are not knowledgeable about SCI and its effects on all body systems and therefore may be reluctant to take on a SCI patient.⁶⁵ Ultimately, due to the lack of accessibility, knowledge and services, the primary care for many individuals with SCI is in the emergency room.

Medical school and residency training usually include little, if any, experiences with physical medicine and rehabilitation (PM&R). Nor does PM&R resident training always expose residents to the full array of primary care services their patients will need although PM&R residents are expected to have at least six months of accredited training in other fields such as family and internal medicine. There is a lack of communication and knowledge exchange between primary care providers and PM&R physicians.^{6, 8, 66}

The limited understanding of physicians can also impact access to durable medical equipment (DME). DME and assistive technology (AT) requires some level of knowledge and functional assessment by a clinician who has expertise in determining which technology would best

fit the person. However, many prescriptions for DME and AT are written by physicians who may have only a basic understanding about how to fit a person with SCI with the appropriate DME or AT. An improper fit can reduce individual's functional capacity and independence.^{5, 7, 67}

Finally, some providers are said to lack “disability literacy” or “disability competence” akin to the notion of “cultural competence” when providers do not fully understand the issues at hand or do not relate to the patient in an appropriate manner. Individuals with SCI report that providers sometimes see their SCI as the primary problem and fail to appreciate their primary complaint that may or may not be related to their impairment. Providers may not understand how various health conditions interact with the SCI. Nor do providers always know how to relate to, and communicate with, an individual with SCI as in the case of speaking to another family member or an accompanying care provider rather than to the individual directly.^{7, 68}

Issues related to health plan coverage and payment

Maintenance rehabilitation can arrest or limit the loss of function for persons with SCI especially as they age. Yet, our health care system usually does not consider maintenance goals and therapy as ‘medically necessary’. Rehabilitation services are reimbursed only when they restore function.^{3, 69, 70} As a result, many persons with SCI do not have access to the rehabilitation services required to maintain a level of functioning needed for independence and participation in their communities as they age.

Access to durable medical equipment (DME) and Assistive Technology (AT) is greatly affected by the haphazard and seemingly arbitrary approval by health plans. Anecdotal evidence abounds about the complicated and exhausting process a person with SCI faces when trying to obtain appropriate technologies: Primary care physicians refusing to write prescriptions because they do not know enough about the technology; payers denying prescriptions or approving such low payments that the person with SCI cannot afford the co-pay and therefore does without the necessary technology.^{71, 72} This is especially true for individuals with tetraplegia who need sophisticated motorized wheelchairs that breakdown often and need to be replaced more often than manual chairs.^{72, 73} A recent NIDRR-funded cross-sectional study found that 59.4% of study participants had wheelchair repairs done in the past 6 months of which 71% were power and 51% were manual wheelchairs.⁷⁴

Many of the barriers that individuals with SCI face are endemic to our larger health care system, a system that competes mainly on risk and prestige, and less on price and quality. Health plans view individuals with SCI as high-risk enrollees that add considerably to their costs and diminish their margins. Without risk-adjusted premiums and without payment linked to outcomes

(e.g., disenrollment rates, rehospitalizations), there is little incentive to serve individuals with SCI well. Under the current system, if health plans serve this population well, there is always the chance it will attract a disproportionate number of high-cost patients. This is the proverbial problem of adverse risk selection that can cause an upward spiral in health plan costs that may make a health plan less attractive to younger and healthier populations. The current system creates incentives to deny payment for some of the health services and equipment that individuals with SCI need.^{7, 12, 70}

Solutions

Over the last few decades, three sets of solutions have emerged to answer the problems identified above (1) patient education and health behavior change, (2) better transitions from rehabilitation care to community health care, and (3) new systems of health care delivery customized to the needs of individuals with disabilities. These strategies are not mutually exclusive; they are mutually reinforcing. In the sections below, we examine each of these strategies, their current state of development, and their implications for future developments in post-rehabilitation health care for individuals with SCI.

Patient education and health behavior change strategies

Education is currently the primary approach used to prevent complications and promote health.⁷⁵ Fortunately, information about SCI is plentiful and readily available: the National Institute for Disability and Rehabilitation Research (NIDRR) funds dissemination centers, rehabilitation research and training centers, and SCI model systems, each of which provide information in a variety of formats about secondary conditions, their etiology, and their prevention.⁷⁶ Disability organizations, such as the National Spinal Cord Injury Association and the Christopher and Dana Reeve Paralysis Resource Center, also have outreach and informational resource centers. In addition, Paralyzed Veterans of America produces and regularly updates its *Yes You Can!* manual⁷⁷ as a resource for individuals with SCI. It produces clinical guidelines^{78, 79} for health care providers to use in clinical practice. The *Yes You Can!* manual, in particular, is widely distributed to many individuals with traumatic SCI who go through rehabilitation. Unfortunately, research has demonstrated that education alone does not necessarily produce behavior change or induce adherence with medical recommendations.⁸⁰⁻⁸³

The psychosocial and programmatic strategies used to encourage individuals with SCI to make recommended lifestyle changes are most often available during inpatient rehabilitation, which may not always be the optimal time for absorbing or learning new health behaviors.^{75, 84-86} Outpatient and community wellness programs are becoming more available for individuals with

disabilities,⁸⁷⁻⁹¹ but these also have their limitations: Group treatments are often not a viable alternative for individuals with SCI living in the community because of barriers associated with personal care attendants, accessibility and transportation.^{92, 93} Often they fail to attract or appear relevant to the groups who need them most.^{94, 95} Beyond issues of attention, literacy, and learning styles, individuals with disabilities from racial and ethnic minority populations often do not feel that such programs address their concerns, strengths, or the health disparities/discrimination they experience within the health system.^{96, 97}

Telephone counseling, telehealth services and Web-delivered services are increasingly popular ways of overcoming distance, transportation and accessibility barriers in promoting the health of people with disabilities. Information and communication technologies can connect patients with clinicians and other members of their care team for direct service delivery, as well as monitoring and follow-up. Telephone counseling and similar approaches can provide information to consumers “just in time,” during the period when information is needed and seen as most relevant. Pilot studies indicate that telehealth strategies provide relevant information, reduce hospital days, and result in positive consumer ratings.⁹⁸⁻¹⁰¹ Two NIDRR-funded randomized controlled trials found that telephone counseling is an effective means of improving quality of life among individuals with TBI following inpatient rehabilitation¹⁰² and increasing health promotion activities among individuals with MS.¹⁰³ Telephone counseling and Internet-based health promotion studies are currently under way within the SCI Model Systems.^{104, 105} However, the use of telehealth and related approaches remains hampered by a lack of reimbursement in most fee-for-service payment systems.

Various “self-management” techniques have been shown to be effective in fostering appropriate health behaviors, increasing self-efficacy, improving compliance with medication regimens, decreasing pain, improving health status, and lowering health-care costs in managing health conditions such as asthma, arthritis, and diabetes.^{83, 97, 106-110} In addition, self-management protocols have been effectively tailored to meet the needs and concerns of minority populations.^{111,}

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Peer support/counseling/mentoring is based on the assumption that individuals who have gone through the same types of experiences—and who are now living or coping successfully—may be best able to provide guidance and assistance to those more newly injured. The relationship of the peer is first and foremost with the individual (with the disability) and the goals of the interaction are generally set by the desires and expectations of one or both of these individuals. The benefits and effectiveness of peer counseling interventions are unclear as research studies have found mixed

results.¹¹³⁻¹¹⁸ However, peer counseling may be especially appropriate for underserved and underrepresented minority groups.¹¹⁹⁻¹²¹

Closely related to the concept of peer mentor is the concept of “patient navigator,” a person who assists the individual in navigating the health care system and, and where necessary, serve as a patient advocate. The concept has its origins in the 1980s in cancer care¹²² and continues to gain traction in addressing the health care needs of people with many other conditions including SCI and stroke and those from underserved populations.^{123, 124} Patient navigators, unlike peer counselors, do not necessarily share the same health condition as the person they are assisting or have a disability themselves. Yet, like peer mentors, patient navigators receive training and supervision from a health care professional. In recent years, the role of patient navigator has expanded to include health education and health behavior change. At least one SCI model system is currently exploring the role of patient navigator in SCI health management.¹²⁵

In many ways, the use of peer mentors, patient navigators, patient advocates, and other forms of patient coaching underscores many of the health system’s underlying weaknesses with respect to access, usability, and responsiveness. The use of third party agents, in one sense, represents a work-around solution to structural barriers in the health system. Apart from addressing the shortcomings of the health care system, studies indicate that patient coaching strategies can improve adherence with medical recommendations, performance within an organization,¹²⁶⁻¹³⁰ and cognitive functioning.¹³¹⁻¹³⁷

Transitions and hand-offs

As patients move from one care setting to another, the transition process can sometimes be fragmented, inefficient, unsafe and expensive. Strategies that reduce some of these “handoff” problems for patients with SCI may include developing a standardized “transitions” data set that identify key data that should be communicated as a patient with an SCI transfers from one care setting to the next.¹³⁸ This work parallels current efforts by the Centers for Medicare and Medicaid Services to develop a standardized patient assessment tool (for the fee-for-service Medicare population) and an associated web-based application of the post-acute care payment reform demonstration.¹³⁹

Some studies indicate that various pre-discharge interventions can help reduce rehospitalizations, lower post-discharge health care costs, reduce emergency room visits, and prevent post-discharge adverse events, while other studies have found small or no effects. One pilot study that involved rehabilitation patients examined the use of a standardized personal health care record (i.e., portable profile, patient care notebook) as a means to improve the discharge process.¹³⁸

More recently, Jack *et al.*¹⁴⁰ evaluated the effectiveness of a comprehensive standardized discharge intervention that included patient education, comprehensive discharge planning, and post-discharge telephone reinforcement in a general medical population, and found that the intervention group had fewer hospitalizations. Collaborations among clinicians and researchers at the model system centers provides a ripe opportunity to develop and test the effectiveness and costs of an evidence-based comprehensive standardized discharge intervention aimed at reducing post-hospital adverse events.

Model health systems

An effective transition strategy presumes that there is a community-based system of health care to which the individual can transition. The opening sections of this paper strongly suggest that there are significant shortcomings in the delivery of post-rehabilitation health care for individuals with SCI. Thus, a more effective transition strategy may be useful if the individual uses other post-acute venues as part of the same episode of care but may have limited utility if there is not an effective health delivery system that can accommodate the ongoing post-rehabilitation health care needs of individuals with SCI.

Over the last three decades, several model community-based primary care programs aimed at select populations have emerged.^{7, 15, 59, 141} They are usually geographically limited programs with very limited enrollments. These programs embrace several of the following features. They ...

1. Incorporate care coordination and case management principles including consumer involvement in care management and design.
2. Use clinical protocols and pathways to address common problems among enrollees.
3. Use clinical information systems that can track patient needs and progress.
4. Use evaluation protocols that emphasize in varying degrees the following: enrollee satisfaction, prevention of secondary conditions, and prevention of readmissions.
5. Dovetail services, where possible, with the personal assistance, assisted living, and long-term care service needs of their target populations.
6. Maintain linkages, partnerships, or other relationships with organized disability groups and other community stakeholders.
7. Use physician extenders such as physician assistants or nurse practitioners.
8. Use home visits as well as office visits.
9. Provide 24/7 availability.

10. Tackle transportation issues related to office visits;
11. Respect patient self-determination and the independent living aspirations of target populations.
12. Encourage self-management and responsibility for maintaining health. And,
13. Take into account patients' mental and behavioral health needs (especially depression) that might otherwise compromise the medical management of other health conditions.

The three best-know programs of this kind include:

- **Urban Medical Group**, also once known as the Community Medical Alliance, in Boston Massachusetts;¹⁴²
- **Axis Healthcare** in Minneapolis/St. Paul, Minnesota;¹⁴³ and
- **Wisconsin Partnership** in Madison ('Community Living Alliance') and Eau Claire (Community Health Partnership, Inc.), Wisconsin.¹⁴⁴

The Urban Medical Group is perhaps the oldest and most emulated. Axis Healthcare is the youngest. Two of these organizations, the Urban Medical Group and the Wisconsin Partnership, had their origins in providing home-based medical care for the elderly before they morphed into organizations that also served working-age adults with disabilities. The Wisconsin Partnership is a spin-off of the PACE [Program for all-inclusive Care for the Elderly] that attempts to integrate the primary and long-term care needs of an older population at risk for nursing home care.

Several rehabilitation centers provide, or until recently provided, some degree of ongoing primary care, although none on the scale provided by the three mentioned here. Examples include programs at Rancho Los Amigos in Downey, California; the Shepherd Center in Atlanta, Georgia; the Rehabilitation Institute of Chicago in Chicago, Illinois; and the Rehabilitation Institute of Michigan in Detroit, Michigan, the last of which had a program in which physiatrists and internists teamed up to provide primary care as a dyad. In addition, the Department of Veterans Affairs maintains a network of 135 primary care SCI teams throughout the nation some of which are associated with one of its 23 SCI centers.

In addition to the 13 features mentioned above, the three model programs cited here have several shared experiences. They . . .

1. Stemmed from a common frustration with the existing health care system as being unresponsive to the needs of individuals with disabilities.

2. Started with a committed leader or two (usually without a disability) who saw a need, had a vision, and remained with the program for a long time.
3. Received Robert Wood Johnson Foundation funding during the early stages of their development.
4. Relied heavily on the federal-state Medicaid program but also served those in other health plans. Most obtained Medicaid waivers (§1115 and §1915) that allowed them to be exempt from select Medicaid requirements such as the ‘state-wideness’ requirement, i.e., the program and services must be available statewide. In short, these programs can also be viewed as Medicaid “carve-outs.”
5. Organized, at one time or another, into managed care organizations for care coordination, capitated payment, or both.
6. Served several hundred or more enrollees, but not thousands.
7. Served individuals with SCI as one of the core groups and use individuals with SCI as a reference group in better serving groups with similar functional limitations.
8. Have not been embraced by mainstream private health plans that see individuals with disabilities as a high-cost population that they would prefer not to attract.

Overall, the history of these programs is mixed. All are highly lauded programs and valued by their enrollees but they have not been widely replicated even though their advantages are acknowledged.* They have demonstrated durability but grafting these programs onto the existing health care system has been challenging and thus may account for the limited uptake. These programs have succeeded in part because they had a local champion and leader who remained with the program for many years.

Chronic care management movement

Many of the strategies used in these model health programs mirror the nation’s increasing awareness about the need to manage chronic health conditions more effectively. In a society where the prevalence of chronic conditions exceeds 100 million, the acute medical model is simply inadequate and ineffective.¹⁴⁵ Innovations in chronic SCI care may benefit from awareness of new developments in how chronic illnesses (e.g., diabetes, congestive heart failure) are being managed in primary care. The chronic care model consists of six interrelated components—self-management support, clinical information systems, delivery system redesign, decision support, health care organization, and community resources. Together, these six elements can produce system reform in

* The only exception is PACE [Program for All-inclusive Care] which has been more widely replicated than others and is identified in federal law.

which informed patients interact with prepared, proactive practice teams. Thirty-two of 39 studies found that interventions based on chronic care model components improved at least one process or outcome measure for diabetic patients, and 18 of 27 studies demonstrated reduced health care costs or lower use of health care services.¹⁴⁶

Role of rehabilitation physicians

Short of reforming the health care system or creating new model systems, some have suggested a need for rehabilitation physicians to take up the mantle of primary care.^{5, 6, 8, 147} Many SCI rehabilitation physicians already provide considerable amounts of informal primary care services. For example, former patients will often call a trusted SCI rehabilitation physician to review a course of treatment suggested by a primary care provider or may seek primary care information in the course of a follow-up outpatient visit. Some rehabilitation physicians, who may also be double boarded in internal medicine, may find that this comes naturally and provide primary care services more overtly. Organized physiatry, however, sees itself primarily as a referral profession, and has been reluctant to embrace primary care as one of its core roles.

Recommendations and the Role of Health Care Reform

Four recommendations

Given the issues outlined above, our *first recommendation* is that the SCI Model System concept should be expanded to be not only a model system of acute and rehabilitative care but also a model system of health care that extends into the community. SCI model system grants have helped leverage improved integration of SCI care during the acute and rehabilitative phases of care. These grants should now also be used to leverage greater integration with the next phase of care, i.e., the individual's ongoing post-rehabilitation care, particularly primary care. We urge that NIDRR make such integration an essential component of the model system concept but leave to individual institutional grantees how such integration should be implemented taking into account local circumstances.

Since some of the challenges are so endemic to the larger health care system and health plan payment policies, we are not prepared to prescribe how local SCI Model Systems should proceed. It is not reasonable to expect a local SCI Model System to engage in a transformation of the local health care system or to develop a parallel system akin to the three model programs mentioned in this report. Such efforts require sustained levels of commitment by large arrays of community stakeholders including non-SCI disability groups, health care providers and health plans. Initially, they also require increased levels of model systems funding that are not on the horizon, apart from

the opportunities in health care reform outlined below. Nonetheless, there are many measures that can help bridge the needs of the individual and the resources of the larger system. These may include use of primary care outpatient clinics, use of regular telephonic follow-up services, use of health navigators, use of 24-hour call-in numbers for emergent appointments, use of web-based telemedicine protocols with video interaction, use of on-line personal health records that could be made accessible to multiple providers as well as the individual user, and many more. How a grantee might proceed will depend, in part, on existing relationships with local health plans and other health providers, degree of information system integration with local physicians and clinics, relationships with other community groups, and the like.

The SCI Model Systems program has always had a commitment to data pooling in the form of the National SCI Database to which individual centers submit key patient data. The database uses two core instruments, Form 1 that obtains data on patients while they are in the model system program and Form 2 that collects data on patient outcomes, readmissions, and related secondary conditions at follow-up. Our *second recommendation* is that a limited number of centers begin to develop and pilot a “Form 3” that will document more systematically the individual’s health care encounters (e.g., rehospitalizations, ER visits, physician office visits, therapy visits) and other health-related experiences after discharge from post-acute rehabilitation. This could be adopted as a “modular project” among 3 or more centers. Form 3 data would provide insight into the experiences that individuals with SCI have with the health care system at different stages in their lives. It would also provide the baseline data that SCI model system program can use to chart a more systemic response to the ongoing health care needs of individuals with SCI.

The module project concept is an example of cross-center collaboration in the SCI models systems program—a major advance in the current SCI model systems program. A second example of collaboration is the use of higher-powered multi-center research studies to answer questions that cannot be answered within the scope of a single-site study. Our *third recommendation* is that the SCI model systems program fund a multi-site study or demonstration project to test one or more approaches to addressing the ongoing health care needs of individuals with SCI. Such a study or demonstration project would create a larger participant pool and foster greater external validity of study findings. Again, we are not prepared to recommend specific studies or demonstrations. We believe that those with local knowledge at each interested center will be in the best position to recommend a study or propose a demonstration project in their respective grant applications.

Role of health care reform

These recommendations dovetail well with many provisions in the Patient Protection and Affordable Care Act (PPACA), the recently enacted health care reform law. The new law includes many market reforms designed to mitigate the high levels of risk competition that disadvantage individuals with SCI who have higher risks for health-related conditions such as those outlined elsewhere in this report.

More importantly, from the standpoint of this report's recommendations, several features embedded in the legislation speak to the organization, delivery, and financing of ongoing health services for higher-risk populations such as those with SCI.¹⁴⁸ First is *bundling of payment for acute and post-acute services* (HR 3590, §3023). Bundling is intended to diminish the rate of hospital readmissions and foster greater care coordination over the entire episode from acute care through post-acute care—a principle very much in keeping with the original SCI model system concept.¹⁴⁹ Second is the “*medical home*” concept that seeks to strengthen the role of health teams in small primary care practices aimed at individuals with high ongoing health care needs (§3502). Third is the “*independence at home medical practice*” demonstration authority that calls for physician and nurse practitioner teams that provide 24/7 home-based primary care akin to the model programs profiled above (§3024). Fourth is the *accountable care organization (ACO)* model, a primary care-focused, physician-based, or physician-hospital organization (PHO) that would be “accountable for quality, cost, and overall care...” (§2706). The new law also provides training and continuing education opportunities for primary care providers in furthering the goals of these initiatives. While aimed at the Medicare fee-for-service beneficiaries, these pilots and demonstrations are intended to be models that can be generalized to other payers.

In addition to these four, the legislation is replete with pilot and demonstration projects designed to support many long-standing suggestions to improve care coordination, chronic care management, and health outcomes especially among higher-need groups. The legislation creates a Center for Medicare and Medicaid Innovation (CMI) designed to encourage the development of new service delivery and payment models that will better serve the needs of various “priority populations” who are not well-served in the current system.

We believe that the new health care reform law provides enormous opportunities for NIDRR as well. We doubt that CMS and a handful of agencies such as AHRQ can administer all the pilot and demonstration projects that have been assigned to them. Our *fourth recommendation* is that NIDRR and the Department of Education enter into one or more interagency agreements that will enable NIDRR to use health care reform funding to support and administer innovative pilot and

demonstration projects aimed at individuals with disabilities such as those with SCI. Such funds could augment the SCI model system program and help underwrite the extension of the model system concept into the community in meeting the ongoing health care needs of individuals with disabilities. Despite best intentions, other agencies tend to overlook the ongoing health care needs of individuals such as those with SCI. NIDRR has a long track record in addressing the needs of select populations and should use its existing grants management capacity to bring the promise of health care reform to these populations.

SCI model system as a platform for innovation in health services delivery

In short, with the passage of health care reform, the nation will be entering a fertile period for experimentation and innovation that should not be missed. We believe that the SCI model systems program is an excellent vehicle to promote advances in SCI care including strategies that can better meet the ongoing post-rehabilitative health care needs of individuals with SCI. The model system centers represent a collection of some of the best programs in the nation. The SCI model system network contributes to a national database, collaborate on modular and large multi-site studies, and meet twice per year to discuss issues of mutual interest. The challenges we face stem not only from the failures of the health care system but also its successes in both saving and extending lives. The SCI model systems network is not the only venue in which to address these changes but it does represent one of the best opportunities the nation has in advancing post-rehabilitative health care for individuals with SCI.

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APPENDIX

Obituary



Andrew I Batavia

Scholar, lawyer, and proponent of the rights of individuals with disabilities to make their own decisions in life and at death. Professor of Health Services Administration, College of Health Professions, Florida International University, Miami, FL, USA. Born in Brooklyn, New York, USA, on June 15, 1957; died aged 45 years on Jan 6, 2003, in Miami, USA, from complications of chronic urinary tract infection.

Andrew (“Drew”) Batavia was a lawyer, a researcher, a teacher, and an author on issues relating to health and disability policy. He sought to bring first-class scholarship to the issues that face individuals with disabilities and, in so doing, bring academic legitimacy to the public policy issues that shaped their lives. Batavia moved easily between government and academia and brought the insights of both sectors to all of his work.

At age 16 years, Batavia survived an automobile crash that left him with a level of quadriplegia just short of having to use a ventilator. After a year of rehabilitation at the Rusk Institute in New York, USA, he rejoined his Lincoln High School classmates in Yonkers, New York, to become their class president. Batavia powered his future with his intellect, a typewriter, and a mouth stick. The next year he entered the University of California at Berkeley, joining the westward migration of young people with disabilities to the San Francisco Bay area where they were breaking new ground as individuals with disabilities in academia and society at large. Later, Batavia would move east again to obtain his law degree from Harvard Law School, Boston, and then back west to acquire a graduate degree in health services research from Stanford University.

Batavia brought his training in law and health services research to bear on many issues relating to US health care in general and individuals with disabilities in particular. After a 2-year stint as a legal counsel with the Health Care Financing Administration, he honed his views about the role of individuals with disabilities in the American health-care system during 5 years as an associate director for health services research with the National Rehabilitation Hospital’s Research Center in Washington, DC. There he established his reputation for scholarly erudition and publication.

In 1990, Batavia was chosen to join the White House Fellows—an elite programme that produces many of the USA’s leaders in government and business. As a White House Fellow, he worked with the Office of the US Attorney General and helped draft the federal regulations that implemented the Americans with Disabilities Act of 1990. During the 1-year programme, the White House Fellows travelled

to China where his colleagues carried Batavia and his wheelchair one stair at a time to the top of the Great Wall. “When we finally reached the top”, said Rob Chess, another White House Fellow, “all of us . . . were suffering from a combination of heat prostration, exhaustion, and muscle lactic acid build-up, Drew was wearing a smile that stretched from Outer Mongolia to the Great China Sea. The Great Wall had finally met its match.”

After his time at the White House, Batavia served briefly as the executive director of the National Council on Disability and later as a legislative assistant to US Senator John McCain. In late 1995, he joined the health law practice of McDermott, Will, and Emery in Miami, before eventually joining the faculty at Florida International University in 1997.

In 1992, Batavia married his long-time attendant, Cheryl Nicholson. In 1996, they adopted Joe and Katey, a brother and sister, from an orphanage in Ekaterinburg, Russia.

An enduring theme in Batavia’s life and scholarly work was a commitment to individual autonomy and the right of individuals to make their own decisions. This commitment came into its sharpest focus in the later years of his life when he became a proponent of physician-assisted suicide. Batavia wrote two amicus briefs on physician-assisted suicide before the Florida and US Supreme Courts and a third in the case of Oregon *vs* Ashcroft. In 2002, he and others founded AUTONOMY Inc, an organisation dedicated to furthering the self-determination of people with disabilities. Batavia’s strong stand on physician-assisted suicide often put him at odds with others in the disability community who believed that society’s willingness to embrace physician-assisted suicide for individuals with disabilities was predicated on their devalued status. As with this issue, Batavia never flinched from taking unpopular positions on issues of health and social policy.

Batavia’s personal writings conveyed a wry self-deprecating sense of humour. He dubbed his home in Miami Beach “Bedlam on the Beach” in honour of his hyperactive household. He warned that guests would have to sing for their meals, if necessary, with the aid of a karaoke machine.

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Gerben DeJong
e-mail:
Gerben.DeJong@MedStar.net