

State of the Science Conference in Spinal Cord Injury Rehabilitation 2011:

Introduction

Steering Committee of the State of the Science Conference

“What’s next?” is a simple question often asked with a mix of anticipation and reluctance, because it may suggest that one knows the present achievements and shortfalls in a given area so that the future can be relatively well-perceived. Over the last few decades, the ‘state-of-the-science’ (SoS) conference framework has provided an opportunity to merge the ‘where we are going’ questions with ‘where we have been’ answers. During the June 2011 joint annual meetings of the International Spinal Cord Society and the American Spinal Injury Association, a State of the Science in Spinal Cord Injury (SCI) Rehabilitation: Informing a New Research Agenda conference was held in Washington, DC.

This conference, the first of its kind for SCI rehabilitation research in the United States, was organized in response to the changing landscape of SCI care and anticipated advancements and accomplishments over the next 10 years. Clinicians, researchers, administrators, as well as people with SCI and their families realize that the available interventions and treatments are causing unprecedented and rapid alterations in our view of SCI care and the outcomes from such severe neurologic trauma. The NIDRR-funded SCI Model Systems program (DeVivo, 2007; Tate, Boninger &, Jackson, 2011) grew out of a need to address the unmet rehabilitation needs of people with SCI, including the long-term support needed for return to the community. Incorporated in

this model are programs and facilities that address the extensive medical, psychological, social and vocational needs of people with SCI in a focused, coordinated system. The critical elements for the SCI Model Systems programs are conducting research that is meaningful and can have an impact on the lives of people with SCI, collecting data that contributes to a longitudinal national database for epidemiological and research purposes, and providing a system of care and services from injury through lifetime follow-up. Although the incidence of traumatic SCI remains relatively low compared to other neurologic trauma such as brain injury, outcome expectations have grown with the genetics and molecular revolution and emerging technologies. At the same time, lengths of hospital rehabilitation stays are shortening and costs are escalating. “What’s next?” is a reasonable question to ask as we consider where SCI rehabilitation research support should be focused.

Planning for the SoS conference began in December 2009 with the formation of a steering (planning) committee and initial outreach to federal and private partner organizations for financial and in-kind support. These inaugural steps were funded by the National Institute on Disability and Rehabilitation Research (NIDRR) to the Shepherd Center in Atlanta, GA. The steering committee consisted of representatives from the NIDRR-funded

SCI Model Systems grantees, the NIDRR-funded Rehabilitation Engineering Research Center on SCI, federal agencies, consumer organizations and professional societies.

Conference plans required that the steering committee also obtain financing to ensure that the best speakers could be recruited and support post-conference dissemination efforts. The committee also sought to minimize the cost for attendees. Partners were recruited to provide intellectual input and to provide financial support of the SoS infrastructure. The partners eventually involved 37 federal agencies and private organizations whose support made the SoS possible because of shared interests and commitment to improve SCI care, rehabilitation and outcomes through research.

The steering committee worked for 18 months to reach a final agreement on the SoS conference content, speakers and format. The committee defined four track themes that cover the broad range of rehabilitation issues encompassing the entire biopsychosocial nature of SCI rehabilitation and research: (1) neurologic and functional recovery; (2) aging and secondary conditions; (3) technology for mobility and function; and (4) psychosocial, vocational and quality of life outcomes. A chairperson with expertise in the topic area was selected for each track and the track chairs, together with the Steering Committee, identified plenary speakers with expertise in each track. In some cases, the plenary presenters were selected from outside the field of SCI rehabilitation research as the issues transcend a particular diagnosis or condition but are relevant to SCI. The plenary presentations provided an opportunity for participants to list: (1)

priority goals, (2) barriers to success, (3) research approaches that are essential to progress, and (4) a vision for the achievements that will define the field in 10 years. The plenary speakers also provided paper drafts relevant to their subject matter, which were posted on the conference website prior to the conference, and subsequently published in this journal issue. Finally, the committee recruited two keynote speakers, one to speak to the importance and relevance of the conference from the lived experience of SCI, and one to highlight the current state of experimental research directed at curing SCI, an important part of the research milieu in which the conference was held. The conference was not focused on advances in experimental procedures to reverse spinal cord injury because this topic is the focus of other organizations and conferences.

In addition to the plenary speakers, each track identified panel discussants who were charged with responding to the plenary presentations and exploring research topics in greater detail within each track. The panels generated considerable discussion which continued in concurrent break-out sessions. A leader facilitated these break-out work groups ; workgroup volunteers recorded recommendations for research priorities and then the authors of the final manuscript in this issue of *Spinal Cord* synthesized the recommendations. Conference participants also provided input through a website. The summary recommendations that follow in the final manuscript of this journal issue were formulated by the more than 450 participants from 29 countries and speak to the diversity and depth of the four tracks, and their complimentary nature. The pursuit and achievement of these

recommendations are ‘what’s next’ in SCI rehabilitation services and research.

In conclusion, this SoS was hosted for rehabilitation consumers, providers, researchers, administrators and policy makers, offering a research agenda for the next 10 years and beyond. It is important to these constituents that these recommendations become a forward leaning milestone. Feedback from rehabilitation providers and individuals with SCI as well as other colleagues in the health care and policy areas regarding the accomplishments of the SoS in 2011 is important to ensure that these recommendations can be implemented. A continuous reassessment of where SCI rehabilitation started and progressed, and where it has potential to move forward provides us with the framework for designing the research needed to advance this broad field .

References

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