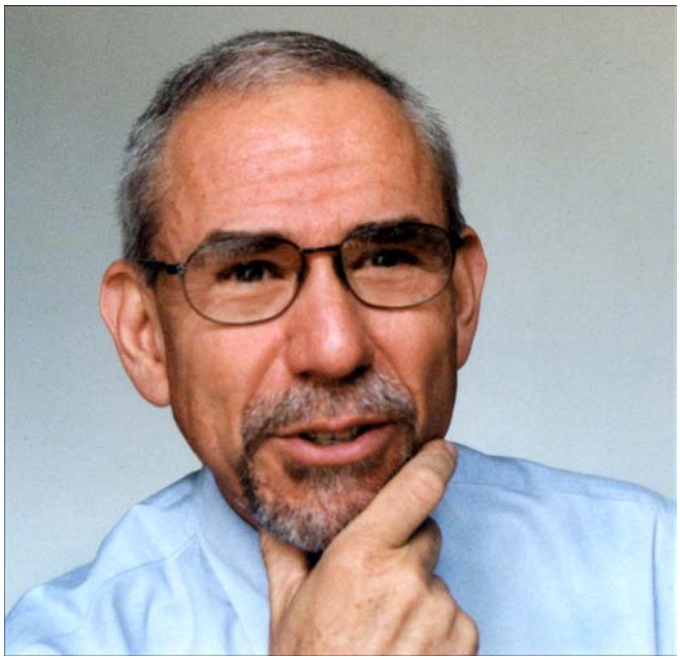
GUEST EDITORIAL

How to succeed in rehabilitation engineering with a great deal of effort



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In the summer of 2000, five individuals, all acknowledged pioneers in the field of rehabilitation engineering (though none wizened, stooped, grizzled, or otherwise visibly battered by their age and experience) gave invited presentations at the annual conference of RESNA, hosted that year in Orlando. In the year after that event, the idea of capturing their remarks on paper and publishing them was gradually transformed by imaginative and dedicated individuals at the JRRD, RESNA and the Rehab R&D program of the Department of Veterans Affairs into a tangible project. I was asked to play sheepdog to this process and these pages attest to its successful conclusion. It has been invigorating and eye-opening to work with these five rehab-engineering pioneers. I appreciate that converting notes on the back of cocktail coasters—meant only to be sufficient to jog creaky memories during a spoken presentation—into organized, accurate readable text is not a terribly edifying task. And so I thank these gentlemen for working with me to prepare the content of this volume.

It wouldn't be unreasonable to wonder why I feel entitled to guest-edit this Special-Topic Supplement to JRRD, *Pioneers in Rehabilitation Engineering*. The answer is simply that any of these gentlemen could legitimately claim me as a true s.o.p. (son-of-a-pioneer), although I don't believe I've actually heard any of them do so. It was Gregg's "nonvocal communication" road show that first educated me in what we now call AAC. That would be back in 1977 or so. And well before that, in 1972 to be exact, Dudley was on the committee, which read my doctoral dissertation at Northwestern and subjected me to the customary 90-minute roast at 450 degrees before handing over the last signatures I needed for my degree. And it was Jim's publications in FES, especially the classic review by McNeil and Reswick, that served as my introduction to that topic. Once, too, he gave me free consulting on design of a uniform-pressure bed meant to be fabricated with only indigenous materials in developing countries. Doug was my predecessor as chair of the Rehabilitation Engineering Program at the University of Tennessee, Memphis. It was a going concern when I got there; too bad about managed care. And then there's Bob. All he did was hire me at MIT, kept faith in me, and spent 18 years mentoring me in research, design, and just generally being a grownup academic.

Whether or not the reader feels these are credible credentials, I will offer some testimony and tentative conclusions of my own, as befits this unique opportunity. I have several comments in reaction to the articles, which follow, and a personal perspective on the field of rehab engineering. The reader gets both for the price of one. My comments on the pioneer pieces can be viewed as a sort of executive summary; the burdened subscriber seeking only a distillation of their observations and wisdom can read the next few pages in one short sitting while saving the full reading experience for her or his next weekend off.

Although the pioneers' articles are historical accounts of particular parts of rehabilitation engineering, enhanced by personal reflections, they can almost be read as manual for any group preparing to start something revolutionary and hoping to sustain

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it once it becomes mainstream. I will attempt paraphrase the implicit and explicit consensus of these authors as a set of generalizations (eleven to be exact) on the conditions and opportunities for building and maintaining a "disruptive" change in standard health care practice.

1. Government funding programs provide an essential (although often clumsy) resource for advancing the revolution, but they need direct shepherding by individuals and well-constituted committees with the insight and energy to keep them viable, effective, and politically attuned to their times. Again and again, all the authors here cited the disproportionate impact of key people and the official and unofficial alliances they formed. Funding programs or no funding programs, productivity and progress are driven largely by the personal zeal of imaginative, charismatic, and ambitious protagonists.
2. The corollary is that politically adept vigilance and activism, at all levels, is essential to preserve even the most "institutionalized" programs and budgets in the face of shifts of policy, politics, and cultural trends. And sometimes even this isn't enough. In academia, hot topics for research and prestige come and go. Department chairs and successful grant getters track and build these trends which can and do displace activities that have lost some of their glamour. Shifting attitudes of political constituencies can drive public agency funding agendas away from programs that were working just fine.
3. Productivity is increased much more than additively when successful collaboration occurs, among individuals as well as agencies and institutions, and across professions. Intimate interactions between clinicians and research scientists and engineers are particularly likely to generate major changes in practice. This is true because of the blending of practical constraints with creativity; and because (in the case of new therapeutic paradigms) early buy-in from influential practitioners greases the skids of change.
4. Product development is best accomplished by designers who are immersed in its marketplace. For AT, this has meant daily informal contact with its consumers. In my own experience, even in a marvelous design hothouse like the Newman lab at MIT, we could not duplicate the advantage I have now, working at NRH just down the hall from individuals who are preparing to live with the effects of spinal cord injury, stroke, and head injury. An interesting caveat from Jim Reswick: there is no reason to believe that designers will be able to conceptualize effective solutions to challenging problems on their first or second try, even with consumer input. (Consumer involvement is necessary but not sufficient.) Hence the need for research and for the unavoidably iterative cycle of prototyping and evaluation.
5. The value of serendipity is unarguable. It can, of course, actively be courted by working hard enough and making contacts freely enough to improve the odds.
6. Graduate students are the sine qua non of academic engineering R&D—and in one sense its most important product.
7. Sound design of assistive technologies must meet all the requirements of good design of any consumer product. Mother Nature and the marketplace never suspend their laws for an instant to honor our good intentions in designing things to help people. AT makes wonderful product design teaching material since it ups the ante for sound human factors, durability, adaptability, reliability, economy and cosmesis.
8. And still on the subject of design, Jim points out explicitly (and I'm confident the other pioneers would agree) that advanced application of technology isn't the same as application of advanced technology. I would add a corollary. Technology that is simple to use on the outside may be complex—may need to be complex—on the inside. I recall, and I'm sure Gregg Vanderheiden does too, the dozens of times I've heard clinicians remark that "because" a particular client was cognitively delayed, a computer was out of the question. This is like saying that a pilot can't possibly fly a jet since the thermodynamics and metallurgy of a turbine engine are outside her ken.
9. One reflection on our pioneers' careers as well as the professional evolutions of numerous other characters to whom they call attention in their articles: Whatever else our field is, it is most definitely a target for application for a remarkably broad range of sophisticated engineering R&D.

A corollary of this is that the researchers and designers who have made substantial contributions have come to our field from every conceivable area of engineering and scientific concentration, often via an epiphany inspired by a particular event or individual.

10. Our challenge as a field—the most important contribution we can make—is enunciation of practical guidelines for optimizing practice; guidelines based on conclusions based on data based on experiments based on powerful unifying bodies of theory. The long-term outcome will presumably be truly evidence-based practice (a notion whose time has come and was, to my thinking, overdue).
11. Our worst behaviors as humans (war, hastily marketed drugs that have tragic side effects, vehicles marketed for pizzazz instead of safety) and our worst episodes of ill fortune (the polio epidemic) seem to provide opportunities to show our very best. Many of the best of current rehabilitative methods, prosthetics, home health systems, and assistive technologies have been spawned by our tragedies.

Another point our pioneers make, directly or not, is that researchers, practitioners, administrators, policy makers, and all others in rehab engineering are compelled to deal with a range of phenomena that goes way beyond engineering and health science. To practice their daily arts and to maintain and advance our field, they need to be alert to effects, relationships, and influences they never learned in engineering school. Speaking of which: I was recently invited to give a short talk at the 2002 meeting of the NARRTC (National Association of RRTC's). With Mitch LaPlante, Joel Myklebust, and Dave Stapleton, I was part of a panel session on "Improving the Integration of Persons with Disabilities: The Contributions of Engineering and Social Science". I was honored and baffled since I didn't believe I knew anything about that topic. I still don't, but I did discover that I have at least formed several convictions from direct experience that seem to fit the topic and may be worthy of generalization. From these personal reflections, I put together a talk called "Top ten intersections of rehabilitation engineering with the social sciences...illustrated."

I'll excerpt eight of those here since they do contribute my own perspective to this editorial.

A. Successful introduction of new assistive and therapeutic technologies into the lives of consumers and professionals is a form of cultural imperialism. It's best that we admit this. Being "sensitive" should mean being good at it, not (necessarily) avoiding it.

Examples:

- Several years ago, my colleagues from the University of Tennessee, Memphis, and I had a small R&D contract with Saturn Automobile on workplace adaptation to accommodate workers recovering from repetitive strain injuries. One crew of men and women from the assembly line vigorously rejected our job accommodation ideas for one particular task because we were "college boys" who couldn't possibly understand their jobs or needs. The ribbing we took continued until we did a really good demonstration of our prototype and found our champion.
- My colleagues here at NRH and at Sister Kenny Institute in Minneapolis have discovered much the same need to build strong individual bonds with particular insiders in their telerehabilitation project on American Samoa.

B: People with disabilities are moving targets for introduction of technology. We need to understand trends, demographics, attitudes, and politics ... or fail miserably.

For example: Many years ago, before words like "medical model" and "consumer" were familiar to me, Cheryl Trepagnier and I introduced an experimental software-based decision guide meant to support rehab professionals and their clients in selection of augmentative communication products. We called it the "Tufts-MIT Prescription Guide". Honest; "prescription". After all, we conducted much of our work at The New England Medical Center. The way our system scored devices for an individual user was driven by her/his wants and needs; but among independent living advocates we had inadvertently identified ourselves with the enemy. And it was a battle I didn't even know about.

C: The age of UAT, Universal Assistive Technology, is upon us.

In the beginning, there was "assistive technology". As Dudley points out in his article in this volume, AT (minus the name) really was with us from "the beginning" (plus or minus a few millennia). Operationally and philosophically, AT is purpose-built

technology meant specifically for people with disabilities. Its function is to close the gap between the demands of a task or environment and the capacities of an individual to succeed in that setting. Good idea; often still is.

Then came the era of universal design. The imperative in this movement is simply to incorporate the needs and abilities of the broadest possible user population in the design of consumer products and the built environment. This approach aims to eliminate (or at least reduce the prevalence of) "disability" by banishing the barriers that create disability. Good idea. This epoch continues to the present.

And now, unheralded or at least much less heralded in the consumer and rehab engineering communities, we hear increasingly frequent noises—substantive reports and hype—about the "smart home." This catchall refers to sensing, interconnection, processing and interface systems, which tie a variety of home systems to each other, and to web-based sources of service and information. The purpose is to provide intelligent personalized assistance to the resident in meeting the demands of everyday life seamlessly and automatically.

What makes the smart home the lineal descendent of AT and universal design, at least in my imagination, is precisely that it is not being marketed primarily to people with disabilities (conventionally defined). But it is based on the premise that typical families today live excessively demanding lives, in other words that there is a "... gap between the demands of [home life] and the capacities of an individual to succeed in that setting" (quoted from above). In other words, the smart home constitutes explicit recognition that we are all disabled (this is fact, not political correctness) and can all use assistance from ... "Universal Assistive Technology". The third era. And you read it here first.

D: The rehabilitation engineer works at the nexus of maybe seventeen cultural divides—some of them more like canyons. Falling in is likely without awareness and finesse.

Three examples:

- Practitioners and research scientists have very different mandates. In the absence of real understanding, they may stereotype each other as by-the-book traditionalists and disconnected theorists, respectively. Meanwhile, rehab engineers are often situated where they need to work productively with both breeds—not to mention playing both roles themselves.
- Physicians and therapists may regard each other across lines of professional power and legal authority in the world of medical practice. The engineer who finds her/himself working as part of a successful mutually respectful multidisciplinary rehab team needs to understand how fortunate s/he is; it hasn't always been like this and isn't universally so now.
- Physicians and biomedical engineers differ in outlook, methodology, training, philosophy, and professional mandate. This is certainly true in rehab, where physiatrists and rehab engineers must play together in order to innovate in clinical and research settings. The doctors need to understand that "their" engineers are not just service staff meant to keep the equipment running; that an engineering education can equip an engineer with the capacity to make conceptual contributions in addition to providing technical expertise. The rehab engineers need to have first-hand understanding of the constraints and demands of everyday health care practice if their innovations are gain acceptance and advance the clinical art.

E: The sentimentalized view of disability is still with us; beware.

For example:

- Most of us have observed, at one rehab engineering conference or another, an unfortunately high tolerance for presentations on unoriginal or ill-founded work. I think this absence of critical appraisal can be credited, at least in part, to the speaker's holiness by association. After all, who would criticize an engineer who came into rehab from a more lucrative branch of industry to build that cute little vehicle for his poor little niece with cerebral palsy? The fact that it's a bad design, which only by luck is a poor imitation of a commercial product the builder knew nothing about, just doesn't matter in the face of such nobility.
- And then there was the era when mandatory "consumer spokespersons" were present at all research presentations. This reflected the sentimentalized idea that all individuals with disabilities magically have well-developed judgment about fundamental research. Consumers on

design teams; consumers on funding policy committees; consumers on review panels, and so forth: Absolutely essential. But a lay person who happens to have an artificial hip sitting in judgment in a conference session on the bearing properties of articular cartilage and the molecular basis of gross tissue properties? Oh please....

F: "Crutch" is still pejorative, as in "Cigarettes are just a crutch for him". And this is just a sign of the pervasive attitude that use of assistive technology constitutes dependence. One particularly significant example is the fact that FIM (the standard outcome assessment tool in clinical rehab) automatically takes away points if any assistive technology is needed for function in activities of daily living. I would argue (and did at a recent meeting of the American Society on Aging) that, for consistency, my need to install and use stairs in my home should be similarly penalized; clearly I am dependent on this AT since I lack the arm strength to fly. The same must be said for chairs since I am disabled by insufficient strength in my quads to maintain a seated position without this assistance; or windows since my retinal sensitivity is too impaired to let me see through walls; or clothing since my thermoregulatory system can't cope with winter without help. It seems particularly ironic that a standard indicator of independence is the ability to drive, when in fact automobiles are obviously assistive technology for people who have lost the capacity to run to work on the beltway.

G: Warning: technology and western scientific method are still suspect in some quarters.

Examples in rehab engineering:

- Reports of "facilitated communication" for people with autism—i.e., placement of the "facilitator's" hand over the hand of the communicating individual to "enable" her/him to select letters and words from a language board—require multiple suspensions of evidence-based disbelief. One must be able to accept the idea that an individual who has had no exposure to reading or spelling, an individual who is looking in a whole other direction when using the board, can compose correctly spelled, well-phrased continuous text describing complex thoughts and feelings. One must be able to accept the idea that the facilitator's hand has no role in guiding the hand of the individual with autism. One must conclude, somehow, that this is more than a Ouija board.
- In the early 1980s, when I was first working somewhere along the boundary between physical therapy and engineering, I attended a two-day symposium in Cambridge meant to bridge the gap between the concepts, language, and mandates of PT and neurophysiology. With greater timidity than I would today, I offered from the audience the opinion that under some circumstances the sensitivity and objectivity offered by instrumented assessment of motor performance could have real value in clinical therapy. A respected figure in the field whose name I may never have known stood in response and disposed of me in one sentence: "Anything that comes between my hands and my patient is just getting in the way." Clearly this attitude has been extinguished to a degree by successful clinical instrumentation and by the ubiquity of technologies of all sorts. But I've observed unfortunate remnants right to the present.

H: Rehab engineers who design AT and systems for universal access are commonly educated to model various aspects of individual function and physiology. They need to be capable, as well, of understanding social phenomena. For example:

- Social science can elucidate the political process, which, in turn, drives funding for rehab engineering R&D and reimbursement for AT service delivery. In fact it often appears to me that our pioneers have had as much effect through their political efforts (formal and informal) as they have through their scientific and technical innovations.
- Social science can also provide a conceptual vocabulary for understanding the marketplace for AT and universal design. To be truly consumer-driven in rehab engineering product design, one must understand at least the salient economic, social, and political facts of being an individual with a disability.

And now, welcome to five papers from pioneers in the field of rehab engineering, people whose contributions are so pervasive that the whole shape of our field is a monument to their vision and work. It is an honor to be able to open for them.

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