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Panel: Furthering National Purposes and People with Disabilities
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1. Introduction and Overview:

Thank you for inviting the Rehabilitation Engineering Research Center on Telerehabilitation (RERC TR) [i] to participate in the Federal Communication Commission's panel entitled *Furthering National Purposes and People with Disabilities.* My name is Katherine D. Seelman, Ph.D. I serve as Outreach Coordinator for the RERC TR. The RERC TR grant was awarded to the School of Health and Rehabilitation Science, University of Pittsburgh, by the National Institute on Disability and Rehabilitation Research (NIDRR) in 2004**.** A second round grant was awarded in October 2009. I also serve as co-research director of the Quality of Life Technology (QoLT) engineering research center which is supported by the National Science Foundation.[ii] QoLT's mission is to transform lives of people with reduced functional capacities due to aging or disability, through the development of intelligent systems that augment body and mind functions.

Telerehabilitation (TR) refers to the use of information and communication technologies (ICT) to provide rehabilitation services to people over a distance.[iii] Telerehabilitation applies not only to health but also to vocational rehabilitation. It encompasses social participation in the health and vocational domains. Telerehabilitation services may include: teletherapy, telemonitoring, teleconsultation, telehealth information, (prevention, primary care), homecare, personal health records, social networking (peer to peer groups) and assistive technology. Health Information Technology (HIT) is closely associated with TR because HIT provides the framework for comprehensive management of health information and its secure exchange between consumers, providers, government and insurers. Broadband provides interactivity opportunities which are used across TR R&D and service delivery.

The need for TR, the opportunities TR provides, and barriers to TR access by people with disabilities are described below using examples from current RERC TR R&D projects. In the future, we hope to provide FCC with a more in-depth presentation of the TR infrastructure developed by our RERC which bridges the gulf between the clinical/health and consumer models. It is scalable, cost-effective by using open-source software, and provides innovative methods for using social networks to engage consumers while protecting confidentiality of the electronic health record. TR and certain emerging smart technology such as intelligent wheelchairs and advanced tracking and monitoring are mostly intended for use in natural, rather than clinical environments-- environments where people live, learn, and work. Research

and development objectives include reducing utilization of nursing homes through improved health care management and increasing the quality, availability and cost effectiveness of long term services and supports. One month reduction in nursing home admissions could save $1.12 B annually (US)[iv] TR is a relatively "young" service delivery mode so that technical performance, usability, cost-effectiveness and consumer satisfaction outcomes research is at a nascent stage. Related national ICT accessibility policy indicators and data collection efforts have not yet been implemented.

The final section of our testimony provides a brief description of emerging advanced technology from which people with disabilities may benefit. An intelligent mobility device (formerly a wheelchair) with a high tech prosthetic limb can enable an end user to perform tasks independently-- such as shopping or opening a door-- and engage more fully in community religious, work and learning activities. R&D and adoption of accessible and affordable TR, HIT and other emerging technology will require market incentives, government mandates and inter-agency coordination, some of which are included as recommendations in this testimony.

2. Need:

People with disabilities number approximately 54 million people in the U.S. They are a functionally diverse population whose functional needs can be met by ICT which is designed to be adaptable. Adaptable and universally designed ICT enables control and navigation as in twisting a knob or clicking a mouse and enables access to content as in sounds, images, and clear and simple language, including sign language, closed captioning and video description. Well-designed ICT empowers people across the age span, but especially people with disabilities and older adults. They need ICT tools to self-manage their health to prevent painful and costly secondary conditions as in the case of people with lymphedema who experience fluid buildup in lower extremities, skin breakdown and non-healing wounds which may be life threatening and which diminish their quality of life. However, ICT tools must be affordable as well as accessible, either through insurance reimbursement or other support.

People with disabilities have unmet and insufficiently met primary care and prevention needs as well as long-term service and support needs. Because health policy has truncated the length of time for in-hospital rehabilitation, people with spinal cord injury, for example, return to the community in need of short and long-term care, services and supports. They and their local clinicians need the following: a) continuing consultation with experts at centers of excellence, b) maintenance and monitoring of health to prevent costly pressure ulcers and infections, c) equipment assessments and adjustments and d) psychosocial and vocational counseling d) social networking to enhance independent living and quality of life. While face-to-face insurance coverage of services may be exhausted, telerehabilitation can meet these community-based needs through the provision of cost effective teleconsultations, teletherapy and teleassessments.

People with disabilities are an underserved population, subject to many health disparities. [v] [vi] Public health legislation does not routinely address the needs of people with disabilities. Access to appropriate health care, enjoyed by most Americans, is problematical, including access to federal health promotion and disease prevention programs and services. People with disabilities are higher than average utilizers of health services but lower than average users of the internet.[vii] Older adults with disabilities, in particular, are low users.[viii] They need accessible, affordable equipment with training and support to access the internet and to purchase, maintain, and upgrade ICT and assistive technology equipment and services.[ix] [x]

People with disabilities, especially those with a severe disability, are underemployed and low income.[xi] They often need job coaching and other employment supports on an episodic, as needed basis, not for regularly scheduled, extended times. Providing clinicians onsite is expensive and may draw attention to the consumer and negatively impact performance. Needed supportive technology may involve sensors in the workplace, reminder prompts delivered by smart phones and portable information interfaces.

3. Opportunities[xii] [xiii] provided by RERC TR:

The RERC TR carries out R&D that involves provision of teleconsultation, telemonitoring, teletherapy, telehealth (prevention, primary care information), telehomecare and remote assistive technology. Examples of RERC TR R&D projects appear below:

- TR infrastructure: Implement a internet-based infrastructure, developed by TR, which is capable of supporting multimodal interaction (text, video, image, audio) for low-cost communications between centers of clinical excellence and local clinician and consumer communities.
- Teleconsultation: Test TR portal and interactive teleconferencing to support Autism tele-assessments of patients and teleconsultation between expert clinicians at a center of excellence and clinicians in rural areas.
- Telemonitoring and prevention: Evaluate teleportal and wireless TR tools as a way to expand to underserved areas a Wellness program which currently is non-virtual, limited by time, and cost of travel but shows excellent clinical outcomes.
- Teletherapy and prevention: Test teleportal, real-time videoconferencing, follow-up monitoring and clinical interventions aimed at improving quality of life through lifelong adherence to self-care of chronic edema/lymphedema in individuals with mobility limitations who use wheelchairs.
- Televocational rehabilitation: Develop an integrated, scalable internet-based system for remote cognitive rehabilitation and job coaching (stored audio and/or video vignettes for job training) for individuals with cognitive disability that can be accessed using portable wireless mobile devices (smart phone).
- Assistive Technology telemonitoring, teleconsultation and on-going training: Use teleportal and teleconferencing to involve client, local clinician, remote clinician, caregivers, family in augmentative and alternative communications assessment and training sessions.

4. Barriers:

- Inadequate broadband accessibility and affordability. Video conferencing, smart phone technology, social networking and Web 2.0 must provide usable content, control, and navigation. Closed captioning, video description and simple language are necessary to access.
- Inadequate accessible and affordable health information technology (HIT), participation by disabled consumers and older adults in planning and rollout and policy coordination across agencies, including the Access Board.
- Inadequate accessibility and usability training and education of consumers, providers and clinicians.
- Lags in regulation of internet-based technology and legislation including existing law such as 508 and 255.
- Inadequate inclusion in public health legislation of people with disabilities.
- Lack of reimbursement and support for mainstream ICT such as smart phones, their maintenance and upgrade.
- Inadequate support for R&D and demonstrations of accessible and affordable telerehabilitation, HIT, SNS, sensors, tracking and monitoring and other emerging technology.
- Inadequate research support for the development of technical, usability, cost and customer satisfaction outcome measures and the development of national policy accessibility indicators and data collection.
- Inadequate incentives to industries and vendors to invest in the development (universal and participatory design) and purchase of accessible systems and equipment.
- Lack of disability accessibility indices with well developed indicators and tool kits for policymakers, industry, providers and consumer groups to show outcomes of policy.

5. Policy recommendations:

- Support public hearings on HIT; require disability and older adult consumer involvement in the development of HIT policy.
- Extend universal service fund to pay for broadband products and services for health and employment.
- Expand Center for Medicare and Medicaid Services (CMS) reimbursement and health delivery policies to support and promote technologically advanced health services, health care, and related use of smart phones and other devices.
- Support the process of ICT standards development for universally designed IP/VIoP technology.
- Support technical, usability, cost and consumer satisfaction outcome studies that can be the basis for promotion of accessible and affordable technologically advanced health and telerehabilitation services and enhance access to health care and community participation.
- Develop disability and clinician ICT usage-related questions for use in national surveys

- Support studies of the reimbursement of ICT for employment by the Rehabilitation Services Administration
- Integrate the Access Board into the development of guidance for advanced ICT technology.
- Develop and implement Disability ICT Accessibility data collection capability; create a data base of best practices using the work of organizations such as ITU and G3ict [xiv] as models.

6. Research from Quality of Life Technology Center (QoLT) engineering research center (ERC):

The NSF-supported Quality of Life ERC develops emerging care and support technology which: a) is sensitive to the person's intent and capability b) forms symbiotic relationships between person and technology c) is person and environment aware (intelligent homes).

QoLT focuses on the needs of older adults and people with disabilities. QoLT technology uses broadband for multimodal data, voice, and audio activities based on the following engineering systems: a) virtual coaches b) active home c) personal mobility and manipulation and d) safe driving. Virtual coach recognizes activities, user's level of task performance, and provides appropriate guidance and feedback. Active home provides manipulation assistance (transfers from bed) with a perceptive environment that provides services in the home. Personal Mobility and Manipulation Appliance is a self-perceptive and intelligent appliance for manipulation and mobility assistance. Safe driving concentrates on ways to make driving safer for older adults and people with disabilities through providing objective feedback on driving capability and route instruction tailored to the user and prevailing road/environmental conditions.

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