RESNA

RESNA's Guidelines and Priorities for Assistive Technology and Rehabilitation Engineering Research

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RESNA's Guidelines and Priorities for Assistive Technology and Rehabilitation Engineering Research: 2017

This document presents RESNA's guidelines and priorities with respect to Assistive Technology (AT) and Rehabilitation Engineering (RE) research. It was originally developed by the RESNA Research Committee, who continues to maintain it with input from the RESNA membership, research-related funding agencies, and other researchers in the field. The document includes two parts; Part I covers research guidelines to govern the methods and approaches used in AT and RE research, while Part II lists specific areas of research relevant to AT and RE.

As a "living document," it is anticipated that it will be updated frequently in response to advances in technology and changes in policy and clinical practice. RESNA's Research Committee will modify the document based on input from the RESNA membership and the field every two years. We hope that the document will serve as the basis for an active discussion among RESNA members. Input from the RESNA membership will be collected through a variety of methods, including on-line surveys and the AT Forum listserv. The resulting document will be published on RESNA's website.

Part I. Assistive Technology and Rehabilitation Engineering Research Guidelines: 2017

The research guidelines below are intended for the research community and related stakeholders including research-related funding agencies, researchers, designers and developers, evidenced-based practitioners and policy-makers. RESNA takes the position that any research that advances the health, independence and quality of life of individuals with disabilities through technology is aligned with RESNA's mission. Therefore, Part I focuses on RESNA's priorities regarding <u>how</u> AT and RE research should be pursued to maximize its likelihood for success and broader impact, while Part II presents RESNA's priorities in terms of <u>what</u> research should be pursued.

RESNA was founded in 1980 and has a unique historical perspective to contribute to discussions between policy makers, funding agencies, engineers, scientists, educators and clinicians. During the past 35 years, the worlds of technology and disability have changed dramatically, and are likely to do so at an even more rapid pace over the next 35 years. It is impossible to predict the new technologies that will emerge, the applications they will enable, or the implications they will have on the lives of people with all levels of abilities. What we can anticipate, however, are that research and development methods and practices related to AT and RE will improve the lives of people with disabilities, which RESNA enthusiastically endorses. Based on documented past work we predict that RESNA members will continue to identify next generation needs, facilitate discovery, train next generation practitioners, prepare researchers for new levels of scholarship, create new research networks, and generally facilitate research.

1) User Involvement:

User involvement is an often stated (and often ignored) criterion for research in AT and RE. Foundations, agencies and organizations that fund AT and RE research should include

input from individuals with disabilities and their caregivers, clinicians, therapists and educators in their funding decisions. Individuals with disabilities and their caregivers, clinicians, therapists and educators should also be involved in the design, evaluation and execution of research, not just as participants in the research. Clearly, some research (e.g., fundamental/bench research, meta-analyses) may have less direct consumer involvement than other research (e.g., clinical evaluation of a technology) but no AT or RE research should be conducted without at least some direct consumer involvement.

2) Cross Disability and Integrated Mass Market Design - Universal Design Approach:
Research in AT and RE should also appreciate that a single technology or intervention can potentially benefit multiple populations if it is designed with this in mind. For example, text-to-speech technology is useful for people who are visually impaired, people who use communication devices and people with literacy impairments. Text-to-speech technology is also useful for people who are "situationally impaired" (but are otherwise "able-bodied") because they are in a location (e.g., a sunny beach) or engaged in an activity (e.g., driving) that prevents them from viewing the screen of their device. Achieving this goal means including a wide variety of users and adopting universal design goals at the beginning of a project, rather than trying to "retrofit" the design later. Similarly, research should also be mindful that some technologies or interventions might reduce barriers for one population but introduce barriers for another. Conducting research with a "wider lens" allows investigators to appreciate both of these possibilities.

3) Leveraging the Disability Research Model:
RESNA points out the countless historic discoveries and societal benefits of R&D focusing on people with disabilities. From brain topographic functional specialization in neuroscience, the implementation of video closed-captioning, or the invention of the telephone, people with disabilities and their interaction with technology have resulted in transformational scientific and health related discovery with societal-level impact. RESNA not only endorses the inclusion of people with disabilities in health and scientific discovery processes in general, it emphasizes that investigations that fail to include people with disabilities and the examination of technology's potential will likely miss major scientific opportunities. In a sense, all technology is designed to *assist*, in that the point of any technology is to help people do things they either could not do themselves or could only do themselves with greater effort. It is imperative that research teams are highly interdisciplinary and include specialists who understand the mechanisms of impairments and their relationships to technology and quality of life.

4) Achievable Translational Goals that Articulate Improved Functional and Quality of Life Outcomes:
AT and RE research should be linked to real or potential improvement in the quality of life of individuals with disabilities. This means AT and RE research should be evaluated based on outcomes relevant to individuals with disabilities. These outcomes may be defined at an individual, group or societal level. Outcomes may not be measurable at the end of a single research project (especially research in fundamental science), but outcomes should still be defined for each research project and considered (along with progress towards those outcomes) when funding decisions are made. An emphasis on the outcomes of research

highlights the need, both scientifically and clinically, for methods to quantify the impact of AT and RE interventions on all aspects of an individual's quality of life.

5) Mixed and Integrated Research Methodologies that Recognize the Personalized Approach to Interventions:

Because of the small user populations for some AT and RE interventions, accumulating sufficient evidence to establish statistically significant effects can be difficult. Research can address this challenge in a number of ways:

- Make use of rigorous "small N" and single-subject experimental designs
- Adopt uniform, replicable experimental designs that allow synthesis and meta-analysis across multiple studies
- Leverage the Internet to aggregate data from multiple studies in a common format accessible to the entire research community
- Encourage the sharing of data and resources developed with public funding.

6) The Unique Challenges of Knowledge Translation in Technology and Disability:

A significant challenge to research in AT and RE is transferring the resulting knowledge, technology and interventions to practice. The traditional market for AT and RE consists of small, fragmented populations of consumers, caregivers, clinicians, therapists, teachers and others who could make use of knowledge and technologies generated by research, but the number of people with impairments and disabilities must be increasingly viewed on an epidemic level. We all have levels of impairment and disability either now or in our personal future. A catastrophic injury can happen to anyone without notice and we all increase our level of impairment through natural aging. The phenomena and science underlying impairment and disability is a continuum even though legal decisions and policymakers often feel that they must draw discrete dichotomous lines that differentiate people with disabilities from the “normal” population.

Knowledge translation is further hampered by ingrained clinical and educational practices that are entrenched by policy and training. A primary culprit is our inflexible medical model, which makes it extremely difficult for novel AT and RE interventions to enter the market if they fall outside the rigid categories embodied by the Healthcare Common Procedure Coding System (HCPCS) code set. Research into measures that scientists, policy makers, practitioners, and the business community can take to increase access to AT and RE interventions is needed. Similarly, research that develops or implements innovative approaches to knowledge and technology transfer should be supported.

7) Cross-Cutting Service Sectors:

Research in assistive technology and rehabilitation engineering is unique in that its successful implementation crosses service sectors. AT and RE interventions target use by individuals that freely move among medical, community health, K-12 schools, higher education, employment, and recreation services and environments. AT and RE interventions usually cannot be implemented in only one domain alone and must be cognizant of translational application across domains. This has substantial implications for the interdisciplinary nature of AT and RE research and its financing.

8) Performance Standards for Assistive Technology:
AT only serves consumers well if it is safe and effective. Standards help assure safety and effectiveness and provide practitioners with additional information as they recommend the most appropriate AT for their clients. Third-party payers benefit by knowing that the AT they financially support will work for the consumer and will address their needs for a reasonable amount of time. Performance standards, while voluntary, provide the framework for determining AT device safety and effectiveness. They are produced by diverse committees, including consumers, practitioners, researchers, regulatory agency personnel, researchers, and testing laboratory professionals.

Part II. Areas of Current and Emerging Technology & Disability Research: 2017

Part II outlines priorities with respect to Assistive Technology (AT) and Rehabilitation Engineering (RE) research areas. The purposes for doing so are:

1. To identify research priorities that have the potential to most impact people with disabilities through improvement of their quality of life;
2. To align the research efforts of our membership with these priorities;
3. To inform research sponsors of these priorities so that they might align their funding levels to the best impact.

The sections below attempt to organize the wide range of relevant research areas, although many of the categories overlap to some extent. Note that the sections are not intended to be exhaustive, but rather to list some key research goals in each area.

Augmentative and Alternative Communication (AAC)

Augmentative and alternative communication (AAC) interventions are used by individuals who have difficulty communicating using speech. AAC technology ranges from extremely complex (e.g., computer systems operated by brain-computer interfaces) to the extremely simple (e.g., letter boards).

Research goals include, but are not limited to:

- Methods for establishing effectiveness of AAC interventions for persons with conditions acquired in adulthood.
- Establishing impact of AAC devices in the development of language and social interaction skills in infants and children.
- Identifying social and personal factors that support the use of AAC devices.
- Best practices for applying mobile devices and information technology in AAC.
- Designing and evaluating new interface technologies to support AAC.
- Leveraging communication context to enhance interaction, including specific support in educational settings to support learning.

Brain-Computer Interfaces

Brain-computer interfaces (BCIs) have applications for individuals with motor impairments, communication impairments, visual impairment, hearing impairment or amputation. BCIs need to have scaled-up input/output, with the ultimate goal of producing thought-provoked action at a distance and establishing noninvasive capability to interface the brain with the computers.

Research goals include, but are not limited to:

- Develop materials, electrodes and implantable devices that are sufficiently bio-compatible for long-term use.
- Develop algorithms for maximizing information transfer between the brain and the computer.
- Implement both brain-to-computer and computer-to-brain communication for feedback control.
- Identifying social and personal factors that impact the transfer of brain-computer interface technologies to real-world use.

Computer and Information Technology Access

Computer and information technology is pervasive and ubiquitous in society today. It includes hardware (e.g., computers, tablets and smartphones), software, websites, and a range of special-purpose systems (e.g., information kiosks, ATMs, electronic voting systems).

Research goals include, but are not limited to:

- Designing and evaluating new interface technologies, including those that incorporate a universal design approach.
- Techniques for providing seamless access across devices, operating systems, user impairments, and usage environments.
- Techniques to adapt access methods dynamically to individual user needs.
- Improving access by people with cognitive disabilities.
- Establishing impact of cloud-based information storage for persons with limited access due to physical, cognitive, language, sensory, economic, or geographic factors.
- Best practices for evaluating, recommending, and adapting computer and information technology to address the needs of differently abled users.
- Collaborating with educators in the support of computer and information technology in the Universal Design for Learning initiative.

Emergency Preparedness

Emergency preparedness is a broad area that includes supports for individuals with special assistance or technology needs in the response to an emergency situation. This should include, but is not limited to, devices related to medication management, electrical backup for power-dependent equipment, evacuation appropriate to individual limitations, communication (both face-to-face and digital) for persons with communication differences, and the care and support of service animals.

Research goals include, but are not limited to:

- Develop a “standardized” interface to allow shelter-in-place and emergency evacuation sites to provide charging capabilities for a variety of assistive technologies (power wheelchairs, augmentative communication devices, etc.).
- Develop technologies for locating and evacuating individuals with disabilities in large-scale events like tornadoes and hurricanes.

- Develop technologies and performance standards for evacuating individuals with mobility impairments from high-rises and other buildings.
- Develop technologies that enable continuous access to personal assistive technology devices, or facilitate tracking to locate devices if they are temporarily unavailable to the consumer.

Ethical Considerations / Privacy and Security

Ethical considerations in the field of rehabilitation and assistive technologies includes the clinical use of unproven or partially substantiated AT interventions, potential implications of technology use (or non-use) on an individual's quality of life, the relative cost of the AT balanced against the actual functional gains associated with the use of the device, and social justice issues related to the fair distribution of scarce resources.

Privacy and security in the field of rehabilitative and assistive technologies can become an ethical concern when devices are used in health monitoring, in personal communications and in monitoring people with physical or cognitive impairments to enhance safety. In these cases personal information may be available to a wide audience. Without careful consideration the technology user may lose the privacy protections available to persons not using technological supports.

Research questions include, but are not limited to:

- When should technology be used / not used?
- How best to make decisions regarding AT for vulnerable populations (e.g., people with cognitive disabilities, children, etc.)?
- Methods of helping developers to incorporate privacy by default in AT (particularly ones that autonomously collect and distribute data)
- Techniques for educating consumers on understanding what data their AT is collecting/using and how to set the privacy/security settings to reflect their needs and comfort level.
- The impact of free and low-cost AT (e.g., open-source software, 3D-printed orthotics and prosthetics, AAC apps) on the sustainability of the AT industry

Functional Electrical Stimulation

Functional electrical stimulation (FES) refers to the use of electrical currents to activate the nerves that innervate extremities affected by paralysis resulting from spinal cord injury (SCI), head injury, stroke, and other neurological disorders.
Research goals include, but are not limited to:

- Develop materials, electrodes and implantable devices that are sufficiently bio-compatible for long-term use
- Develop control strategies that provide for more precise controls of the hand and fingers to improve performance of activities of daily living
- Implement feedback control.

Home Health and Independent Living

Home Health and Independent Living refer to supportive care, services, or technologies provided in the home or provided for making the home more accessible. Research in this

area focuses on optimizing the independence of people with disabilities in the living environment of their choice, while ensuring safety and health needs are met.

Research goals include, but are not limited to:

- Develop smart home technologies that provide environmental controls for those with disabilities
- Develop home monitoring technologies that support health and safety for those living independently
- Develop best practice guidelines for providing physical access through home modification services
- Determine best practice guidelines for optimizing functional independence in the home and beyond.

Information Technology and Telecommunications

Technologies and concepts that fit within this category include, but are not limited to:

- the cloud
- the Internet
- big data
- mobile devices
- electronic health records
- ubiquitous computing
- Internet of Things
- cybersecurity

Research goals include, but are not limited to:

- Exploit the power of cloud computing and telecommunications technology to collect outcomes data from, and deliver information and services to, small user populations dispersed across a large geographic area
- Develop technologies, standards and regulations that ensure equal access to electronic information
- Integrate assistive technologies with medical information systems and electronic health records
- Develop services that use "crowdsourcing" to implement solutions that cannot be performed by technology alone
- Capitalize on telecommunication and mobile health technologies to help broaden the accessibility and affordability of modern health care and extend it to remote environments.
- Develop authentication alternatives that are accessible to people with disabilities

Intelligent Assistance

This area applies artificial intelligence and other forms of intelligent assistance to the needs of people with visual impairments, cognitive impairments, and learning disabilities.

Research goals include, but are not limited to:

- Develop way-finding and path planning technologies that are useful for individuals with visual impairments, individuals with cognitive impairments and individuals

with mobility impairments who may need to choose a route with specific features (such as a route with no stairs)
- Develop inexpensive technologies for indoor navigation that can be effective in un-instrumented real-world environments
- Develop task guidance tools that help individuals with cognitive or sensory impairments accomplish complex multi-step tasks
- Develop prompting and adherence technologies that prompt individuals to perform daily living tasks like taking medicine or weight shifting and work-related tasks.
- Develop more realistic text-to-speech voices (including prosody) for communication aids for people with complex communication needs, screen readers for individuals with visual impairments and educational technologies for individuals with learning disabilities
- Incorporate advances in deep learning and natural language processing to improve vocabulary-finding algorithms to speed speech generation in communication devices
- Integrate "Internet of Things" technologies into intelligent assistance aids
- Develop technologies that prevent individuals with cognitive impairments to wander, or allows them to be found more easily when they do wander.

Knowledge and Technology Transfer
This areas focuses on applying research knowledge and technology developments directly to enhance AT practice and better meet the needs to individuals with disabilities.

Research goals include, but are not limited to:
- Develop standards for integrating assistive technologies (e.g., environmental control, augmentative communication, alternative computer access and wheeled mobility) and "mainstream" technologies (e.g., smartphones)
- Explore whether the "crowdfunding" model can be used within the assistive technology industry
- Develop and adopt a framework for development to support the design, creation, testing, and uptake of assistive technology, engineering, and other products to improve the lives of people with disabilities.
- Develop clinical practice guidelines that synthesize the research and provide clinicians with evidence-based guidance for a particular patient diagnosis or problem

Manufacturing Technologies
This area of research refers to the application of new and existing manufacturing processes to improve fabrication of customized assistive technologies for people with disabilities.

Research goals include
- Exploit the capabilities of micro-electrical mechanical systems (MEMS) within assistive technologies through embedded sensors, processors, and actuators
- Explore how low-cost 3D printing, the open-source movement and the "maker culture" can be leveraged to produce inexpensive assistive technologies.

Mobility
Mobility devices includes manual wheelchairs, power wheelchairs, scooters, rollators, walkers, canes, crutches and any other external aid used to assist or replace ambulation. It doesn't include orthotics and prosthetics (separate category) or transportation (separate category).

Research goals include, but are not limited to:

- Design mobility devices that can be easily produced in the developing world
- Utilize lighter and stronger materials in the construction of mobility devices.
- Design child-friendly devices to meet the unique needs of children with special needs

Orthotics and Prosthetics
The Orthotics and Prosthetics area focuses on the application of new technologies to support (orthoses) or replace (prostheses) body parts or related functions. While orthotics usually refer to musculoskeletal applications, prosthetics often have a broader scope including the replacement of various body structures or functions in general. For example, limb prostheses are most commonly understood, but eye prostheses, or cognitive prostheses are other applications used in this context. This area of research includes the more traditional and broader applications related to disability and impairment. Note that this area does not usually include body organ replacement.

Research goals include, but are not limited to:

- Use rapid prototyping and additive manufacturing techniques to deliver prosthetics and orthotics that fit better, last longer, cost less, and take less time to fabricate
- Develop adjustable, expandable, and fully capable prostheses that permit adjustment for growing children
- Use robotics and MEMS technologies to develop more lifelike prosthetics
- Develop a prosthetic retina for patients with degenerative disorders of the retina, such as retinitis pigmentosa and macular degeneration
- Develop prosthetics and orthotics appropriate for the developing world
- Develop smart prosthetics and orthotics that would adapt to tasks and specific environments
- Develop technologies that can collect and standardized outcomes data for comparative effectiveness of prostheses and orthoses.

Outcomes Research in AT and RE
Outcomes research helps us understand whether and why AT interventions are meeting their intended purpose for users. The paucity of outcomes data affects many stakeholders in the assistive technology (AT) field, including clinicians, researchers, manufacturers, and consumers. This adversely influences funding decisions for consumers, hampers clinicians who need to demonstrate the value of their service delivery programs, and makes it difficult for manufacturers to demonstrate the cost-effectiveness of their products. Traditional medical models of outcomes measurement, such as blinded randomized controlled trials (RCTs), are extraordinarily difficult to perform in the AT domain.

Additionally, the numbers of devices, technology strategies, and the implicit personalized approach of AT and RE applications have historically complicated outcomes research and an accumulation of evidence in this field.

Research goals include, but are not limited to:

- Develop outcomes databases relevant to AT and RE that follow the individual across service delivery models and disabilities.
- Research the cost, benefit, and comparative effectiveness relationships between interventions that employ AT and RE and those that do not.
- Develop predictive models for recommending when AT or RE works by itself and in conjunction with other interventions.
- Develop and research new integrated and smart outcomes technologies embedded in AT and RE devices.
- Research how to leverage low cost mass market data acquisition technologies to document outcomes of AT and RE interventions.

Policy and Advocacy

This area relates to the examination of how policies, regulation, and social systems affect the lives of people with disabilities in regard to their access to and use of assistive technology devices and the related assistive technology and rehabilitation engineering services.

Research goals include, but are not limited to:

- Identify the impact of policy changes on outcomes related to persons with disability
- Identify the influence of educational policies governing inclusion and AT provision on educational outcomes for students with disabilities
- Identify the impact of workplace accommodation policies on employment and vocational outcomes for people with disabilities
- Identify the impact of health care reimbursement policies on outcomes for people with disabilities
- Understand the effect of policy on AT and RE service delivery models
- Determine best practices for advocacy and the influence of advocacy on policy formation.

Robotics and Automation

This area includes research in robot-assisted therapy; assistive robotics (wheelchair-mounted robot arms, intelligent mobility aids, robot "assistants"); advanced prosthetics; virtual presence robots; and smart environments and smart automation integrated into live, work and play environments.

Research goals include, but are not limited to:

- Develop robotic actuators that are sufficiently fast and powerful to be useful but safe enough to interact directly with humans
- Develop sensors that are sufficiently accurate, reliable, and inexpensive for integration into commercial assistive technologies

- Integrate "Internet of Things" technologies into electronic aids to daily community activities and living.
- Develop "robot companions" to increase independence in home environments

Support Surfaces and Positioning
Support Surfaces are devices designed to assist with maintaining posture and managing interface pressures. They are typically used to address minimization of interface pressures and optimization of function by encouraging appropriate postures. Support surfaces are used in upright seated postures as well as in prone, supine, and side-lying positions. They include wheelchair seating and positioning equipment, as well as mattress and mattress overlays.

Research goals include, but are not limited to:

- Develop interventions that prevent or lessen the duration and severity of pressure ulcers
- Develop support surface and positioning products that can be produced locally in the low- and middle-income countries
- Develop intelligent dynamic support surfaces that reposition the user throughout the day
- Develop cognitive aids that remind the user to perform pressure relieving activities.

Telemedicine and Telerehabilitation
Telemedicine and telerehabilitation refer to the use of communication technologies (e.g., video conferencing, web conferencing, teleconferencing) to deliver rehabilitation services to an individual who is not in the same physical space as the practitioner.

Research goals include, but are not limited to:

- Develop and evaluate best practices for applying telemedicine approaches to AT.
- Leverage existing tele-technologies in ways that are effective for AT service delivery.
- Gather evidence that can be used to advocate for reimbursement for telehealth services.

Translational Interventions that Bridge Home, Community, & Health Systems
This area focuses on the application and translation of existing knowledge in the areas of assessment, intervention, and training across service provision arenas, as well as socioeconomic, and sociocultural environmental contexts.

Research goals include, but are not limited to:

- Develop screening instruments with acceptable sensitivity and specificity, to determine functional ability and assistive device use across the lifespan
- Develop outcome instruments sufficiently responsive to measuring change in daily life activities, including activity and participation associated with the use of assistive technology devices and services
- Develop and evaluate strategies for identifying and/or measuring the health impact of AT and RE interventions on activity engagement and participation in daily life.

- Create AT and RE assessment and outcome measures that intentionally bridge service sectors. e.g. acute care to inpatient rehabilitation to outpatient rehabilitation to community programs to long-term care
- Evaluate AT and RE interventions and determine whether they increase the ability of people to "age in place" in their homes delaying or eliminating the need to move to other facilities.
- Evaluate AT and RE interventions and determine whether their efficacy varies across service provision arenas, as well as socioeconomic, and sociocultural environmental contexts.

Transportation

This area of research broadly pertains to all modes of local and long-distance travel for individuals with disabilities. In general, these research goals involve making transportation-related activities as independent and safe as possible.

Research goals include, but are not limited to:

- Develop effective and usable wheelchair tiedowns and occupant restraint systems for public transportation vehicles and private vehicles
- Develop accessible vehicle controls that are compatible with "drive-by-wire" cars and "driverless" cars
- Develop efficient technologies for boarding and leaving a plane for people with disabilities
- Develop an inexpensive and reliable method of loading and transporting a power wheelchair or scooter in a private vehicle.

Universal Design

Universal design (UD) is an approach intended to encourage the creation of products and environments that are intuitive and easily used by all end users, not simply those from low-prevalence populations such as people with disabilities. As this intervention and preventative approach for people with disabilities is relatively new, little research has been performed to understand what universal design strategies work best, in what situations, and how universal and equitable they are in impact. Additionally, evidence to support a compelling business case for UD is needed to encourage designers to embrace UD.

Research goals include, but are not limited to:

- Create readily deployable tools and strategies that enable designers to incorporate UD considerations into their existing design processes without incurring undue burden or costs.
- Research the cost, benefit and comparative effectiveness relationships between UD interventions and with other non-UD approaches.
- Quantify and document the evidence that UD contributes to improvements beyond the function of people with disabilities, but serves as a mechanism of improvement for broader populations and society as a whole.
- Track and identify new areas where universal design is needed.
- Develop a theoretical framework and predictive models for understanding when UD is sufficient by itself and when additional interventions are required.