

DEPARTMENT of HEALTH and HUMAN SERVICES

National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR)

2019 Report to Congress

Prepared by ADMINISTRATION FOR COMMUNITY LIVING



Table of Contents

Acronyms	3
Executive Summary	4
Funding and Grants Management	4
Productivity and Accomplishments	4
Research Capacity Building	5
Training and Technical Assistance on the Americans with Disabilities Act (ADA)	5
Knowledge Translation	6
Ongoing Activities	6
Introduction	7
Grant Competitions – Year in Review	9
Grant Competition and Peer Review Process	9
Grant Competitions	9
Monitoring and Oversight	10
Funding Overview	11
Grantee Activities and Progress	14
Sampling of Key Accomplishments by Funded Researchers	16

Abbreviations

AAC	Augmentative and Alternative Communication
AAC-RERC	Augmentative and Alternative Communication Rehabilitation
	Engineering Research Center
ABI	Acquired Brain Injury
ACL	Administration for Community Living
ADA	Americans with Disabilities Act
APR	Annual Performance Reporting System
ARRT	Advanced Rehabilitation Research Training Project
ASTM	American Society for Testing and Materials
CL&P	Community Living & Participation
CHRIL-F	Collaborative on Health Reform and Independent Living
	Fellowship
DRRP	Disability and Rehabilitation Research Project
EMP	Employment
FCC	Federal Communications Commission
FIP	Field-Initiated Project
FY	Fiscal Year
GM	General Motors
H&F	Health & Function
HHS	Department of Health and Human Services
ICDR	Interagency Committee on Disability Research
IDD	Intellectual and Developmental Disabilities
КТ	Knowledge Translation
MSI	Minority-Serving Institution
NIDILRR	National Institute on Disability, Independent Living, and
	Rehabilitation Research
NRTC	National Research and Training Center on Blindness and Low
	Vision
PE	Progressive Employment
RERC	Rehabilitation Engineering Research Center
RRTC	Rehabilitation Research and Training Center
RTT	Real-Time Text
SBIR	Small Business Innovation Research
SCI	Spinal Cord Injury
STI	Strategies, Techniques, and Interventions
ТВІ	Traumatic Brain Injury
VR	Vocational Rehabilitation
VSD	Visual Scene Display
WSU	Washington State University

Executive Summary

The mission of the Administration for Community Living's (ACL) National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) is to generate new knowledge and to promote its effective use to maximize the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities of all ages.

NIDILRR programs address a wide range of disabilities and impairments — across all age groups — and promote health and function, community living and participation, and employment. To accomplish these goals, ACL invests in research, knowledge translation, and capacity-building activities through its discretionary grant-funding mechanisms.

Funding and Grants Management

ACL funded a total of \$100,935,565 to NIDILRR program grantees in FY 2019. In addition, ACL awarded \$8,034,435 in contracts and other support activities in FY 2019. These funds supported 220 grant awards in 2019.

The peer review process for NIDILRR program grant competitions is highly rigorous, with 14 percent of applicants receiving new grant funding during FY 2019 (see Table 1).

Productivity and Accomplishments

ACL funds research toward the development of new knowledge and innovative technological devices, prototypes, measurement tools, interventions, and informational products to enhance community living, health and function, and employment among people with disabilities. Grantees employ advanced methodologies to conduct research, including randomized controlled trials, longitudinal studies, and qualitative studies. These investments produce peer-reviewed publications, intervention protocols, software, databases, and a wide range of other outputs and outcomes. Selected examples of grantee accomplishments in FY 2019 include:

FIRST CLINICAL PRACTICE GUIDELINE FOR MANAGING CARDIOMETABOLIC RISK AFTER SPINAL CORD INJURY (SCI)

Cardiometabolic risk factors are known to affect people with or without disabilities. Cardiometabolic risk factors are often termed the "silent killer" because individuals may never know they carry these risk factors. Despite the presence of these risk factors following SCI, no clinical practice guidelines on this topic are available for use by physicians and other health care providers. As a result of their hard work, Dr. Mark Nash and his colleagues at the University of Miami have produced the first clinical practice guideline for managing cardiometabolic risk after SCI. A description and discussion of this guideline can be found in the <u>Sampling of Key</u> <u>Accomplishments Funded</u> Researchers section of this report.

MANUFACTURERS AND DEVELOPERS OF AUGMENTATIVE AND ALTERNATIVE COMMUNICATION (AAC) HAVE ADOPTED VISUAL SCENE DISPLAYS (VSD)

Prior to the development of VSDs funded by a grant to the Augmentative and Alternative Communication Rehabilitation Engineering Research Center (AAC-RERC), the only AAC option was traditional grid displays with isolated symbols presented in rows and columns. Therefore, it was difficult for many adults with disabilities to use these traditional grid displays, resulting in significant language and cognitive limitations.

VSDs offer an easier alternative to traditional grid displays. They go beyond standard pictures and symbols organized in rows and columns by providing information on the situation or context. As a result of the continued efforts of the AAC-RERC and their partners, this VSD technology has been successfully transferred to a wide range of major AAC manufacturers and app developers.

<u>"YOUDESCRIBE" IS CREATING UNPRECEDENTED ACCESS TO VIDEO MATERIALS FOR BLIND</u> <u>STUDENTS AND ADULTS</u>

Currently, blind individuals have virtually no access to video materials unless they pay for a professional service, which can be extremely expensive and a cost burden on the individual. Researchers and engineers at the Smith-Kettlewell Eye Research Institute have created a better, more cost-effective solution to this problem called "YouDescribe." Since blind individuals are limited with experiencing a visual experience with videos, they must rely on audio descriptions. Audio description is an extra soundtrack added by a describer so that the blind viewer is aware of what is occurring on the screen. Family members, educators, friends, and service providers volunteer to develop the audio descriptions. For more information on how "YouDescribe", visit their support and user information page at https://youdescribe.org/.

Research Capacity Building

Research capacity-building efforts under the Advanced Rehabilitation Research Training Projects, Switzer Fellowship Program, and Disability and Rehabilitation Research Center grant efforts, develop a diverse cadre of emerging disability and rehabilitation researchers. In addition, ACL directs targeted resources to minority-serving institutions, such as Historically Black Colleges and Universities and Tribal Colleges and Universities, to develop and implement programs to build disability and rehabilitation research capacity.

Training and Technical Assistance on the Americans with Disabilities Act (ADA)

ACL sponsors the ADA National Network, which delivers training, technical assistance, and dissemination of materials to stakeholders with rights and responsibilities under the ADA. The ADA Participatory Action Research Consortium complements the Network's activities through

research on factors influencing the community living of individuals with disabilities at regional, state, and community levels.

Knowledge Translation

ACL is committed to ensuring that the products of its sponsored research and development are used to promote the independent living, health and function, employment, and community living outcomes of individuals with disabilities. Through its Knowledge Translation Centers, ACL ensures that new knowledge and products gained through research and development are effectively communicated to stakeholders and used to improve the lives of individuals with disabilities.

Ongoing Activities

In March 2019, ACL published NIDILRR's FY 2018–2023 Long-Range Plan, which outlines the vision and research agenda for NIDILRR programs for the coming years. The ACL Administrator has identified five pillars: *Connecting People to Resources, Supporting Families and Caregivers, Strengthening the Networks, Protecting Rights and Preventing Abuse, and Expanding Employment Opportunities*. These pillars encompass both aging and disability, and NIDILRR's research and subject matter expertise will support planning and implementation efforts in all five areas.

Strategic partnerships with other agencies in the Department of Health and Human Services (HHS) and across the federal government are also instrumental in advancing the research and impact of ACL's NIDILRR. ACL will continue to enhance its existing partnerships and seek out new collaborative opportunities within HHS and more broadly across the federal disability and rehabilitation research communities. ACL's Director of NIDILRR serves as the delegated Chair of the Interagency Committee on Disability Research (ICDR). Under the ICDR Chair's leadership, efforts will focus on building upon the ongoing work of the ICDR and the achievement of goals set forth in the recently drafted government-wide disability and rehabilitation research strategic plan.

2019 Report to Congress

Introduction

The National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) is committed to improving independent living and community participation among people with disabilities by funding research and development in the areas of community living and participation, health and function, and employment. This Annual Report to Congress will describe activities and accomplishments during the 2019 fiscal year. It begins with a summary of the organization's historical foundation, provides a description of its funding process and fiscal allocations, and follows with descriptions of programmatic outcomes impacting the community. This report concludes by describing ongoing initiatives and directions within the organization.

NIDILRR was established by Congress to conduct research that would lead to improved health and function, employment, and community living outcomes of individuals with disabilities. First constituted as the National Institute on Handicapped Research by the Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments of 1978 (P.L. 95–602), amending the Rehabilitation Act of 1973, the organization was originally housed in the Department of Health, Education, and Welfare, and later the Department of Education. The 1986 amendments to the Rehabilitation Act changed the agency's name to the National Institute on Disability and Rehabilitation Research. On July 22, 2014, the agency was renamed the National Institute on Disability, Independent Living, and Rehabilitation Research and transferred from the Department of Education to the Administration for Community Living (ACL) within the Department of Health and Human Services (HHS). This change occurred with the passage of P.L. 113–128, the Workforce Innovation and Opportunity Act. Thereafter, NIDILRR personnel officially became HHS/ACL employees in February 2015.

NIDILRR'S mission is to generate new knowledge and promote its effective use to maximize the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities of all ages. To accomplish this mission, NIDILRR:

- Supports research, development, training, technical assistance, and related activities to build new knowledge.
- Promotes the transfer, use, and adoption of technology for individuals with disabilities to improve health and function, employment, and community living and participation outcomes.
- Provides for advanced research training to increase the number of qualified researchers, including researchers with disabilities and from minority backgrounds.

• Fosters widespread dissemination and use of scientific and technological information to advance policy, practice, and services that improve outcomes of people with disabilities.

NIDILRR programs address community living and participation, health and function, and employment outcomes of people with disabilities. Investments in research, development, knowledge translation, and capacity-building activities are carried out through the following discretionary grant-funding mechanisms:

- **Rehabilitation Research and Training Centers (RRTC)** conduct advanced research and training on a wide variety of health, rehabilitation, employment, and community living topics.
- **Rehabilitation Engineering Research Centers (RERC)** conduct rehabilitation engineering research and development toward technological solutions to rehabilitation problems or environmental barriers.
- **Disability and Rehabilitation Research Projects (DRRP)** conduct research, development, technical assistance, training, and utilization activities related to health, rehabilitation, employment, and community living topics.
- Americans with Disabilities Act (ADA) National Network projects conduct research and provide information, training, and technical assistance to ADA stakeholders.
- Small Business Innovation Research (SBIR) projects support small businesses to explore the feasibility and develop or evaluate the commercialization potential of new technology products for people with disabilities.
- **Knowledge Translation** projects promote the use of research-based knowledge and products among the community of disability research stakeholders.
- Field-Initiated Projects (FIP) conduct 3-year studies on topics proposed by applicants to address a wide range of disability and rehabilitation topics.
- Model Systems programs in spinal cord injury (SCI), traumatic brain injury (TBI), and burn injury conduct research on rehabilitation and long-term outcomes of individuals with these conditions. Research in these programs includes collaborative, multisite research and collection and analysis of longitudinal data.
- Advanced Rehabilitation Research Training Projects (ARRT) support institutions of higher education to provide advanced interdisciplinary research training to postdoctoral Fellows.
- **Research Fellowship Programs, or Mary E. Switzer Fellowships,** are awarded to qualified individuals to conduct 1-year independent research projects.
- Section 21 projects focus on research capacity building for minority-serving institutions, including Historically Black Colleges and Universities and other institutions with significant racial/ethnic minority student populations. Section 21 of the Rehabilitation Act requires that 1 percent of NIDILRR program appropriations be invested to address traditionally underserved populations.

Grant Competitions – Year in Review

Grant Competition and Peer Review Process

ACL's NIDILRR sponsors disability and rehabilitation research and development in the outcome domains of community living and participation, health and function, and employment. Funding is provided to the research community through its funding mechanisms, with priorities within these mechanisms determined by the agency. A rigorous peer review process is utilized for all research grant competitions, as required by authorizing statute and federal regulation. Internal and external program evaluation is also critical in ensuring the quality of sponsored research and development activities. Subject matter experts, with the appropriate credentials and content knowledge, evaluate the scientific, technical, and management aspects of proposals submitted in response to funding opportunity announcements. This approach generates an average score across reviewers, reducing bias and facilitating the ranking of projects by scientific merit, and only the highest-ranking proposals for funding.

Grant Competitions

Table 1 provides a snapshot of NIDILRR program FY 2019 grant competitions. The number of eligible applicants, review panels, reviewers, awards made, and percentage of applicants receiving funding are shown. A large percentage of applications receive high peer review scores that indicate strong technical merit and significant need. Due to the limited nature of program funds, only a small percentage of applicants receive grants each year.

Grant Opportunity	# Eligible Applicants	# Panels	# Reviewers	# Awards Made	% of Applicants Receiving Funding
ARRT H&F	6	1	5	1	16.7%
ARRT CL&P	5	1	5	1	20%
ARRT EMP	6			1	16.7%
SBIR Phase I	41	4	20	10	24.4%
SBIR Phase II	15	2	9	4	26.7%
Switzer Fellowship	44	4	16	6	13.4%
FIP	134	14	70	17	12.7%
FIP – MSI	12	1	5	1	8%
Field-Initiated DRRP in CL&P	40	4	20	2	5%
Field-Initiated DRRP in H&F	32	3	15	1	3%
DRRP AT	26	2	10	3	11.5%
DRRP KT	19	2	10	3	15.8%

Table 1. NIDILRR Peer Review Process Overview, FY 2019

Grant Opportunity	# Eligible Applicants	# Panels	# Reviewers	# Awards Made	% of Applicants Receiving Funding
DRRP IL	5	1	5	1	20%
RERC Hearing	4	1	5	1	25%
RERC ICTA	2	1	5	1	50%
RERC – STI	7	1	5	1	14.3%
RERC Cognitive	5	1	5	1	20%
RRTC CL&P Youth SMI	1	1	5	0	0%
RRTC EMP Psychiatric	2	1	5	1	50%
RRTC Fam Support	7	1	5	1	14.3%
RRTC FI EMP Transition Youth	10	1	5	1	10%
RRTC FI EMP IDD	2	1	5	1	50%
RRTC HF PD	7	1	5	1	14.3%
RRTC Transition Youth EMP					
SMI	2	1	5	1	50%
Total	434	50	245	61	14%

Source: U.S. Department of Health and Human Services, Administration for Community Living, National Institute on Disability, Independent Living, and Rehabilitation Research. These figures do not include two employment-related FY 2019 awards made from 2018 funding decision memos.

Monitoring and Oversight

An Annual Performance Reporting (APR) System, formative review mechanisms, and close monitoring of grant activities provide rigorous oversight of its funded initiatives. The APR is a web-based grants performance system which allow grantees to provide data about goals and objectives, staffing, budget, research and development methods, progress, outputs, and accomplishments. Staff use this data to monitor grantees' work and to determine whether continuation of funding should be provided. For most new grantees, the first reporting period begins on the start date of the award and extends until May 31 of the following year. Subsequent reporting periods begin June 1 and end May 31; however, grantees are required to submit their progress reports annually on July 1.

Formative evaluations of funded awards are used as supplemental oversight and technical assistance tools for grantees. Such reviews are conducted when program officers believe that a grantee could benefit from targeted technical assistance, in addition to technical assistance provided by the program officer. A panel of subject matter experts is chosen to provide the technical assistance and make recommendations for improvement if needed.

Staff, as experienced program administrators and researchers, are highly adept at maintaining ongoing, routine communication with and oversight of grantees to help inform their scientific programs and ensure that they are meeting goals and objectives. Program officers use the HHS Grants Policy Administration Manual to provide consistent oversight across projects. Risk assessments are conducted to identify grantees who are at risk for poor performance, however additional oversight and technical support can be provided as needed. Though rare, findings of ongoing poor performance can lead to a discontinuation of funding to a grantee.

Funding Overview

The allocation of FY 2019 grant funds for the 11 funding mechanisms discussed above is displayed in Table 2. For each funding mechanism, the table includes the number of new and continuation awards. The overall grant allocations across all 11 funding mechanisms totaled \$100,935,565 for FY 2019.

Funding Mechanism (NIDILRR- Funded Centers and Projects)	Award Type (NIDILRR- Funded Centers and Projects)	FY 2019 # of Awards	FY 2019 Total	Grant Amount in Thousands of \$	Grant Amount Total
RRTC	Continuations	14	20	11,949	17,198
RRTC	New Awards	6	20	5,249	17,198
RERC	Continuations	13	17	11,994	15,694
RERC	New Awards	4	17	3,700	15,694
DRRP	Continuations	21	32	10,946	18,103
DRRP	New Awards	11	32	7,157	18,103
ADA Network	Continuations	12	12	12,424	12,424
ADA Network	New Awards	0	12	0	12,424
SBIR	Continuations	3	17	844	2,930

Table 2. NIDILRR-Funded Centers and Projects: Funding and Awards, FY 2019

Funding Mechanism (NIDILRR- Funded Centers and Projects)	Award Type (NIDILRR- Funded Centers and Projects)	FY 2019 # of Awards	FY 2019 Total	Grant Amount in Thousands of \$	Grant Amount Total
SBIR	New Awards	14	17	2,086	2,930
КТ	Continuations	7	10	3,416	4,004
КТ	New Awards	3	10	588	4,004
FIP	Continuations	30	46	5,991	9,190
FIP	New Awards	16	46	3,198	9,190
Model Systems SCI	Continuations	15	15	7,398	7,398
Model Systems SCI	New Awards	0	15	0	7,398
Model Systems TBI	Continuations	18	18	8,462	8,462
Model Systems TBI	New Awards	0	18	0	8,462
Model Systems Burn	Continuations	5	5	1,850	1,850
Model Systems Burn	New Awards	0	5	0	1,850
ARRT	Continuations	15	18	2,178	2,628
ARRT	New Awards	3	18	450	2,628

Funding Mechanism (NIDILRR- Funded Centers and Projects)	Award Type (NIDILRR- Funded Centers and Projects)	FY 2019 # of Awards	FY 2019 Total	Grant Amount in Thousands of \$	Grant Amount Total
Switzer Fellowships (one-year grants)	Continuations	0	6	0	430
Switzer Fellowships (one-year grants)	New Awards	6	6	430	430
Section 21	Continuations	4	5	1,425	1,625
Section 21	New Awards	1	5	200	1,625
Total			220		101,936

Source: U.S. Department of Health and Human Services, Administration for Community Living, National Institute on Disability, Independent Living, and Rehabilitation Research.

Exhibits 1 and 2 illustrate the distribution of funded research and development grant projects in FY 2019 across the three domains of NIDILRR programs: *health and function, community living and participation,* and *employment.* "Cross-cutting" is a composite category used in the Annual Performance Report to describe projects that reflect two or more domains. Roughly 49 percent of development projects and about 31 percent of research projects were described as cross-cutting. "Research projects" are defined as "an intensive systematic study, based on a clear hypothesis or research question that is directed toward producing new scientific knowledge about the subject or problem being studied." "Development projects" are defined as "the use of knowledge and understanding gained from research to create materials, devices, systems, or methods beneficial to the target population, including design and development of prototypes and processes."





Source: U.S. Department of Health and Human Services, Administration for Community Living, National Institute on Disability, Independent Living, and Rehabilitation Research. *2019 Annual Performance Reports*. "Program Performance Report Table 9."



Exhibit 2. Development Grant Projects by Domain, FY 2019

Source: U.S. Department of Health and Human Services, Administration for Community Living, National Institute on Disability, Independent Living, and Rehabilitation Research. *2019 Annual Performance Reports*. "Program Performance Report Table 11."

Grantee Activities and Progress

ACL collects output data through the APR. Grantees are required to report each output from their funded activities in one of four categories: publications; tools, measures, and intervention protocols; technology products and devices; and informational products. A brief description of each category of output type follows:

• **Publications** are documents directly funded by a grantee's current award. Publications include journal articles, periodicals, web journals, proceedings from meetings and symposia, books or

book chapters, monographs, abstracts, technical or research reports, and reviews. Within this output category are peer-reviewed and non-peer-reviewed publications.

- **Tools, measures, and intervention protocols** include instruments or processes created to acquire quantitative or qualitative information, knowledge, or data on a specific disability or rehabilitation issue as well as research-based protocols for delivering interventions to specific target populations of people with disabilities.
- **Technology products and devices** are developed, modified, tested, or evaluated by the grantee. This category refers to any technology product or device developed under the award that the grantee disseminated or delivered to external audiences during the current reporting period.
- Information products refer to items such as training manuals/curricula, fact sheets, newsletters, audiovisual materials, marketing tools, educational aids, websites, presentations, and other forms of disseminated information.

Exhibit 3 compares the number of output products produced by grantees within each category type in FY 2019. Additional detail has been provided for the category of publications, with peer-reviewed and non-peer-reviewed publications being reported separately.

Exhibit 3. Total Outputs Produced by All Grantees across All Program Mechanisms, by Product Type, FY 2019



Source: U.S. Department of Health and Human Services, Administration for Community Living, National Institute on Disability, Independent Living, and Rehabilitation Research. *2019 Annual Performance Reports*. "Program Performance Report Tables 18–22."

Data obtained through the 2019 APR show that ACL supported 220 grantees during FY 2019, totaling \$100,935,565 across all program mechanisms. These projects reflect the breadth of disability and rehabilitation research within the agency's outcome domains of community living and participation, health and function, and employment. The knowledge and products that are generated by research and development grants have a wide variety of important impacts in the field. The summaries that follow provide examples of the outcomes and impacts resulting from

NIDILRR program investments. Additional information concerning these projects is available through the National Rehabilitation Information Center website (<u>http://www.naric.com/</u>).

Sampling of Key Accomplishments by Funded Researchers

NIDILRR program grantees conduct coordinated, integrated, and advanced programs of research, development, training, and knowledge translation.

The following are examples of accomplishments reported by grantees in FY 2019.

First Clinical Practice Guideline for Managing Cardiometabolic Risk After SCI

<u>Cardiometabolic risk factors</u> affect people without disabilities and people with disabilities. In both people with and without disabilities, cardiometabolic risk factors are often termed the "silent killer;" anyone may have these risk factors and never know it. People with spinal cord injuries are different – supporting the need for specific guidelines to manage cardiometabolic disease risk in people with SCI.

Thanks to a grant entitled <u>A Lifestyle Intervention Targeting Enhanced Health and Function for</u> <u>Persons with Chronic SCI in Caregiver/Care-Receiver Relationships: Effects of Caregiver Co-</u> <u>Treatment</u>, Dr. Mark Nash and his colleagues at the University of Miami and Medstar Rehabilitation Hospital at Georgetown University are working on this problem.

As a result of their hard work, Dr. Nash and his colleagues have produced the first clinical practice guideline for managing cardiometabolic risk after SCI. A description and discussion of this guideline can be found in the following publication:

Nash, M. S., Groah, S. L., Gater, D. R., Dyson-Hudson, T. A., Lieberman, J. A., Myers, J., Sabharwal, S., & Taylor A. J. (2018). Identification and management of cardiometabolic risk after spinal cord injury: Clinical practice guideline for health care providers. *Topics in Spinal Cord Injury Rehabilitation, 24, 379–423*. Full text of the clinical practice guideline: (<u>HTML format</u>).

Physicians and health care professionals, responsible for identifying and treating secondary health conditions occurring after SCI, will now have access to, and be able to use, this clinical practice guideline to provide better care to patients with SCI. Persons with SCI and their families can also bring this guideline to their health care providers and engage in a discussion with their health care providers about how to incorporate the recommendations into their plans of care.

Manufacturers and Developers of Augmentative and Alternative Communication (AAC) Have Adopted Visual Scene Displays (VSDs)

Prior to the development of <u>VSDs</u> by the grant awarded to the Augmentative and Alternative Communication Rehabilitation Engineering Research Center (AAC-RERC), the only AAC option

was traditional grid displays with isolated symbols presented in rows and columns. It was difficult for many adults with disabilities resulting in significant language and cognitive limitations to use these traditional grid displays.

VSDs offer an easier alternative to traditional grid displays. They go beyond standard pictures and symbols organized in rows and columns by providing information on the situation or context. Put more simply, VSDs are photos or pictures that people can use to communicate messages to others. These images depict familiar scenes, objects, or people, and users can touch "hot spots" on the photo to speak messages that relate to the pictured scene or object. For example, a person with aphasia might touch a hot spot on a picture of a sibling and say, "this is my sister." This additional information on the situation and context makes it easier for persons with complex communication needs to express their wants and needs and therefore enhances their ability to interact and participate with others in the community. Research from the AAC-RERC and external researchers demonstrates the effectiveness of VSDs with adults with severe chronic aphasia, primary progressive aphasia, dementia, and other conditions.

Due to the continued efforts of the AAC-RERC and their partners, this VSD technology has been successfully transferred to major AAC manufacturers and app developers.

The widespread integration of VSD technology into AAC devices by these manufacturers and developers offers speech-language clinicians and practitioners effective and easier-to-use options to help their clients. With appropriate guidance from speech-language clinicians and practitioners, individuals and families with complex communication needs can use these VSD-enhanced AAC devices and software applications to improve their ability to communicate with much less effort.

Information on the availability, effectiveness, and use of VSD technology in AAC is also much more commonplace in the scholarly literature. Examples of publications that discuss it include but are not limited to:

Mooney, A., Bedrick, S., Noethe, G., Spaulding, S., & Fried-Oken, M. (2018). Mobile technology to support lexical retrieval during activity retell in primary progressive aphasia. *Aphasiology*, *32*, 666–692.

Taylor, S., & Wallace, S. (2019). High technology AAC in post-stroke aphasia. *Perspectives of the ASHA Special Interest Groups*, *4*, 464–473.

Thiessen, A., Brown, J., Freeland, T., & Brewer, C. H. (2019). Identification and expression of themes depicted in visual scene and grid displays by adults with traumatic brain injury. *American Journal of Speech-Language Pathology, 28*, 664–675.

Waller, A. (2019). Telling tales: Unlocking the potential of AAC technologies. *International Journal of Language & Communication Disorders*, *54*, 159–169.

Childes, J. M., Palmer, A. D., & Fried-Oken, M. B. (2019). Communication support before, during, and after treatment for head and neck cancer. In P. C. Doyle (Ed.), *Clinical care and rehabilitation in head and neck cancer* (pp. 247–264). Springer.

<u>General Motors (GM) Withdraws its Federal Communications Commission (FCC) Petition for</u> <u>an Exemption to Certain Real-Time Text (RTT) Regulations</u>

RTT is an important technology for many persons with disabilities, especially those with communication or hearing difficulties, because it allows instant text transmission and receipt without having to press a "Send" button. Instant text transmission is similar to the instantaneous exchange of information that happens during a voice telephone conversation. This instant text transmission is particularly important in emergency situations. The FCC recognized the importance of RTT by adopting a set of federal RTT regulations found in <u>47 CFR Part 67</u>.

In December 2018, GM submitted a <u>request for a waiver to some of the FCC RTT requirements</u> with respect to its new autonomous vehicle ride-hailing service but then <u>requested and</u> <u>received approval to withdraw this request</u>. The withdrawal of this request was due in large part to the <u>comments</u> and ongoing consultation with researchers and consumer groups at the <u>RERC on Universal Interface and Information Technology Access</u>.

The RERC worked with consumer groups on the development of these <u>formal comments</u> to the FCC, pointing out that a waiver was unnecessary since the law and regulations as written already exempted the technology for which GM was looking for an exemption and that instead the FCC should simply respond that an exemption was not needed since the regulation did not cover GM's use case.

Issuing an exemption would have created a loophole for other covered organizations to avoid compliance with the federal RTT regulations. Consulting directly with GM over a period of time resulted in GM realizing they did not need an exemption. Additionally, GM cited the RERC and consumer group <u>comments</u> as evidence supporting the withdrawal of their waiver request.

Factsheet Entitled "The ADA, Addiction and Recovery" Helps Addiction Professionals

Many people in recovery from addiction are unaware of their civil rights under the ADA. The ADA applies to addiction to alcohol, and to the illegal use of drugs differently. To address this situation, the New England ADA Center, as well as expert members from the ADA National Network Knowledge Translation Center, developed a factsheet in PDF format entitled <u>The ADA</u>, <u>Addiction and Recovery</u>.

News of the availability of this factsheet spread and Kristin Hamilton, Director of Communication for the <u>National Association for Alcoholism and Drug Abuse Counselors</u>, decided to include the <u>factsheet in the May 2019 issue of their national association's online</u> <u>newsletter</u>. This is an important step for dissemination of ADA addiction-related information because the Association's membership represents the professional interests of more than 100,000 addiction counselors, educators, and other addiction-focused health care professionals in the United States, Canada, and abroad.

Free Short Courses on Blindness and Visual Impairment Provide New Knowledge to Those Who Take Them

The <u>National Research and Training Center on Blindness and Low Vision (NRTC)</u> offers free-ofcharge <u>short online courses</u> to everyone, with the purpose of increasing knowledge about blindness/low vision, employment of people who are blind/visually impaired, and center research results.

Based on current 2019 information reported by NRTC, 769 people accessed these online courses and completed 1,712 courses with a passing grade. Most of the users were VR professionals, but users also included educators, individuals with who are blind/visually impaired, friends and family members of these individuals, and VR administrators.

These courses are quite popular with state VR agencies. Virginia Department for the Blind and Vision Impaired and South Carolina Commission for the Blind use these courses for training of their new staff. Georgia Vocational Rehabilitation Agency uses these courses as a component of trainings that they provide to their staff. Individual users are also taking the courses on NRTC's website.

"I took multiple courses from the NRTC Continuing Education page. I found that the information on employer relations and use of Business Relations employees in VR agencies to be particularly helpful in describing to VR Counselors in my agency the importance of opening up to the employer/business side of our work. This has been useful to help them understand that when we reduce stigma, fears, etc. of employers our participants can have greater success."

"With this course, I was better able to understand the different causes of low vision and how the different types of low vision create barriers. I also learn about resources to help people with low vision and blindness. Learning to read an eye report was also very helpful."

"Assisting my father who has macular degeneration and has low vision."

Standards Developed by NIDILRR Program Grantee are Foundational to New Proposed Federal Legislation on Accessible Fitness

Little information on accessible fitness equipment, exercise or fitness classes, and instruction is available to individuals with disabilities. Dr. Jim Rimmer and his colleagues at the <u>RERC on</u> <u>Exercise and Recreational Technologies for People with Disabilities</u> have been working to solve this problem for several years.

Through ongoing research and development efforts led by Dr. Rimmer and his colleagues, an <u>American Society for Testing and Materials (ASTM)</u> standard entitled <u>Standard Specification for</u> <u>Universal Design of Fitness Equipment for Inclusive Use by Persons with Functional Limitations</u> <u>and Impairments (ASTM F3021–17)</u> has been developed. The first of its kind, this specification establishes the requirements for the design and manufacturing of fitness equipment intended for use by persons with functional limitations and impairments. It aims to assist designers and manufacturers in reducing the possibility of injury when these products are used in accordance with the manufacturer's operational instructions. It covers assistive technologies such as wheelchairs, walkers, crutches, canes, prosthetics, alternative communication devices, and cell phones, as well as requirements for color contrast.

These standards have been used by Federal legislators to help define "accessible exercise or fitness equipment" in <u>S.3728</u>, the Exercise and Fitness for All Act, which was introduced in the 115th Congress in December 2018. The act was reintroduced in the 116th Congress as <u>S.1244</u> on April 30, 2019. The act will require the <u>Access Board</u> to create guidelines regarding the provision of universally designed and inclusive fitness equipment, programming, and staff trained in working with people with impairments. As of April 2019, 30 advocacy organizations had pledged support of the bill.

A related bill (H.R.4561) with the same name was introduced in the House of Representatives on September 27, 2019.

<u>"YouDescribe" is Creating Unprecedented Access to Video Materials for Blind Students and Adults</u>

Individuals who are blind have virtually no access to video materials unless they pay for a professional service, which is extremely expensive. Researchers and engineers at the <u>Smith-Kettlewell Eye Research Institute</u> have come up with a better, more cost-effective solution to this problem.

They have developed "<u>YouDescribe</u>." Since individuals who are blind cannot see videos, they must rely on audio description. Audio description is basically an extra soundtrack added by a describer so that a viewer who is blind knows what is happening on the screen. Family

members, educators, friends, and service providers volunteer to do the descriptions. For more information on how YouDescribe works, visit their <u>support and user information page</u>.

YouDescribe is generating a lot of excitement. In the past 6 months alone nearly 900 people have opened YouDescribe accounts, bringing the total to close to 2,500 subscribers, and 600 new, high-quality videos have been posted. An interesting short YouDescribe video is <u>the 2017</u> <u>Solar Eclipse</u>. Currently approximately 15 videos are being described per day. Center staff are very active on the <u>YouDescribe twitter account</u>, keeping YouDescribe viewers abreast of exceptional content from volunteers.

Center staff also maintain a <u>YouDescribe Facebook</u> page, which highlights great audio description, presents mini tutorials, and posts articles about audio description in general. This structure creates a community of practice for teachers and keeps them growing as audio describers in and out of the classroom. One volunteer describer recently used YouDescribe to hone her skills and build a portfolio of excellent described videos, which she was then able to use to apply for and obtain a job as a professional describer for CaptionMax. This is one of the largest providers of closed captioning and media access in the U.S., whose clients include Warner Brothers Television, NBC Universal, and Sony Pictures Entertainment.

Finally, third-party websites are citing and talking about YouDescribe. Examples include but are not limited to:

- Perkins School for the Blind Review of YouDescribe
- Media Access of Australia How to Audio Describe a YouTube Video

Progressive Employment (PE) Fidelity of Implementation Toolkit May Help States Correctly Implement PE

There is a critical need for innovation to ensure that persons with disabilities who have multiple work barriers, limited work skills or educational credentials, and who may have a need for intensive work experience opportunities are not left out of a system-wide initiative to align public employment services with business needs.

One potentially innovative model that can address this critical situation is known as the <u>PE</u> <u>Model</u>. Researchers wrote the first peer-previewed publication on PE. The citation for this publication is below:

Moore, D., Haines, K., Bradshaw, H., Porter, A., Smith, J., & Foley, S. (2018). Development of the Progressive Employment dual customer model for vocational rehabilitation. *Journal of Vocational Rehabilitation*, *49*(2), 149–160. <u>View abstract</u>.

Moreover, Researchers at the University of Massachusetts at Boston, working on a 3-year grant entitled <u>Progressive Employment for Individuals with the Most Significant Disabilities</u>, have

developed a Progressive Employment Fidelity of Implementation Toolkit. The Toolkit provides: (1) an overview of the PE Model; (2) definition of terms; (3) key principles of PE; (4) prerequisites for operationalizing PE; and (5) the revised Fidelity of Implementation Measurement Tool (version 4.3). This Toolkit is important because it can be used to guide implementation of the PE Model in a variety of settings and provide a quantitative measurement (score) of fidelity to the key model components to inform research and practice. The <u>PE Learning Collaborative</u> has informed the development of the Toolkit through site visits, Learning Collaborative meetings, and by direct input.

This fidelity of implementation toolkit is not widely available yet. However, the Toolkit has been shared with <u>researchers at the American Institutes for Research (under Maine's Work-Based Learning grant)</u> as well as <u>Mathematica Policy Research</u> current and former staff. It was also shared with state VR agencies implementing PE. Examples of states implementing PE include but are not limited to <u>Maine</u> and <u>Vermont</u>.

In Maine, a contractor is using the Toolkit to inform the current evaluation of PE expansion within the state. VR agencies may use the tool to assess fidelity of implementation across area offices/statewide. VR agencies can review measurement indicators and provide or request additional training in content areas related to PE implementation strategies.

These examples of current uses of the Toolkit, as well as other future uses, will help to ensure that the PE Model is being implemented as intended. Ultimately, implementing PE as intended will help maximize employment outcomes among people with disabilities who face multiple work barriers, have a limited set of work skills, and limited educational credentials.

Anti-Stigma Curriculum Helps Veterans with Psychiatric Disabilities in California and Massachusetts

NIDILRR-funded <u>researchers at Boston University's Center for Psychiatric Rehabilitation</u> have been working on interventions to reduce feelings of stigma among people with psychiatric disabilities.

In a previous funding cycle, these researchers developed and tested the <u>Anti-Stigma Photovoice</u> <u>Curriculum</u> with individuals with psychiatric disabilities. News of this anti-stigma curriculum has spread, and clinicians in the Department of Veterans Affairs (VA) health systems in Massachusetts and California are currently using it to treat stigma and internalized stigma among veterans. For more information on how the curriculum is being used by the VA Palo Alto health care system in California, email <u>Dr. DiAnn Aiello</u>, psychologist and local recovery coordinator. For more information on how the curriculum is being used by the VA health care system in Massachusetts and other states, email <u>Dr. Zlatka Russinova</u>, a staff member at Boston University's Center for Psychiatric Rehabilitation.