

Interagency Committee on Disability Research

Government Wide Strategic Plan
FY 2017-2020



INTERAGENCY COMMITTEE ON
DISABILITY RESEARCH

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Government Wide Strategic Plan FY 2017-2020

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Introduction

This document contains a description of the Interagency Committee on Disability Research (ICDR), the planning process to develop the Government Wide Strategic Plan for FY 2017-2020, and the strategic goals and objectives the ICDR will pursue over the next three years. Background materials and resources used to develop this plan are available on the [ICDR website](#) at icdr.acl.gov. The materials include [Working Group Research Gaps, Problem Statements, and Final Priorities](#) and [Federal Disability Initiatives](#). Please send inquiries about this draft plan or the ICDR, to ICDRinfo@neweditions.net.

The Workforce Innovation and Opportunity Act (WIOA) (Public Law 113-128) included a new requirement for the ICDR to develop a comprehensive government wide strategic plan for disability, independent living, and rehabilitation research. The plan must include:

- a description of measurable goals and objectives, existing resources each agency will devote to carrying out the plan, timetables for completing the projects outlined in the plan, assignment of responsible individuals and agencies for carrying out the research activities, and research priorities and recommendations;
- a description of how funds from each agency will be combined, as appropriate, for projects administered among Federal agencies, and how such funds will be administered;
- the development and ongoing maintenance of a searchable government wide inventory (GWI) of disability, independent living, and rehabilitation research for trend and data analysis across Federal agencies;
- guiding principles, policies, and procedures, consistent with the best research practices available, for conducting and administering disability, independent living, and rehabilitation research across federal agencies; and
- a summary of underemphasized and duplicative areas of research.

Coordinated by the ICDR, this government wide strategic plan is the culmination of a year-long effort to gain consensus on its guiding principles for success and methodologically produce a document that capitalizes on potential interagency synergies and reflects the priorities of the WIOA-defined stakeholders: policymakers, representatives from other federal agencies conducting relevant research, individuals with disabilities, organizations representing individuals with disabilities, researchers, and providers.

The ICDR and statutory agencies have considerable work ahead to complete a comprehensive government wide strategic plan containing all of the components mandated by WIOA. This report contains the overarching framework that undergirds the strategic plan, specific goals and objectives for the next three years, with a crosscutting thematic approach that emphasizes transparency, accountability, inclusion of the stakeholder community, and coordination with other existing and emerging federal interagency efforts.

Background

According to the Centers for Disease Control and Prevention, over 22% of Americans experience a disability and that number is expected to increase markedly with the aging of baby boomers.¹ People with disabilities experience significant disadvantages—lower employment rates and annual earnings; lower educational attainment; inadequate access to housing, transportation, technology, and health care; and greater likelihood of living in poverty.² The rate of disability is higher for individuals who are American Indian/Alaskan Native and African American than for those who are white.³ The need for disability research that can help improve the quality of life of all people with disabilities is pressing.

Funding for a wide range of disability related research is dispersed across numerous federal agencies. Additionally, a number of agencies responsible for disability programs and policy do not fund research, but use research-based evidence. The ICDR has been authorized by WIOA to serve as the body to coordinate the government wide strategic plan. The ICDR has a long history of promoting collaboration and coordination across the government to meet the needs of the disability community and effectively leverage available resources. The authorizing legislation appears in [Appendix A](#) and more details on the ICDR are provided in [Appendix B](#).

Mission

To promote coordination and cooperation among federal departments and agencies conducting disability, independent living, and rehabilitation research programs including programs relating to assistive technology research and research that incorporates the principles of universal design.

Vision

The ICDR will be widely recognized for facilitating and coordinating federal interagency efforts, and for promoting collaborative relationships that maximize the best use of federal resources for disability, independent living, and rehabilitation research.

¹ Centers for Disease Control and Prevention. July 31, 2015. Morbidity and Mortality Weekly Report, *Prevalence of Disability and Disability Type Among Adults — United States, 2013*. 64(29), 777-783. Available at:

<http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6429a2.htm>

² National Council on Disability. October 2011. *National Disability Policy: A Progress Report*. Available at:

http://www.ncd.gov/progress_reports/Oct312011.

³ Centers for Disease Control and Prevention. October 7, 2011. Morbidity and Mortality Weekly Report, *QuickStats: Percentage of Adults Aged ≥18 Years with a Complex Activity Limitation, by Race/Ethnicity* --- National Health Interview Survey, United States, 2003—2009. 60(39), 1361. Available at:

http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6039a9.htm?s_cid=mm6039a9_w.

Guiding Principles for Success

As a first step in developing this plan, the ICDR, with the assistance of an outside facilitator, developed guiding principles to clarify its role and purpose. These principles also serve as guideposts in the plan development process.

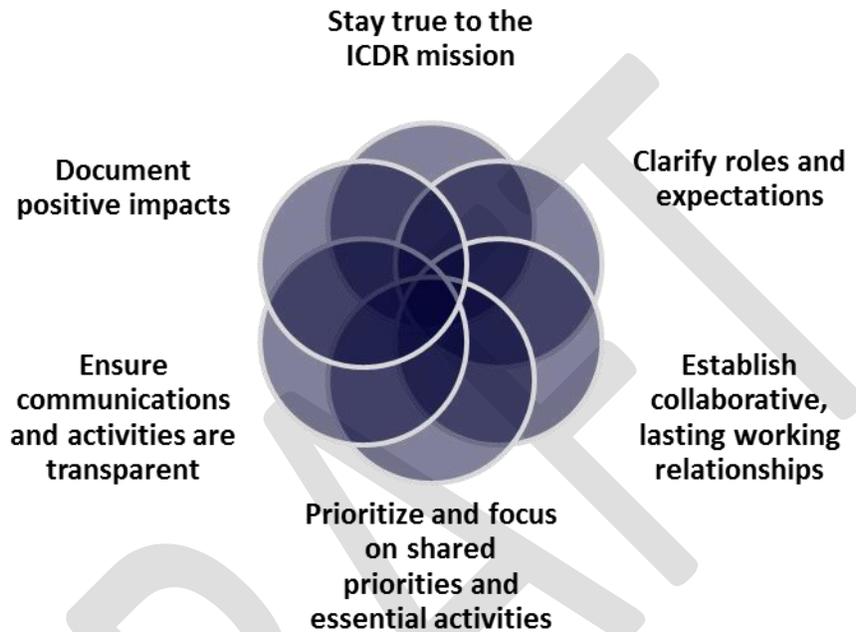


Figure 1. ICDR Guiding Principles

- 1. Stay true to the ICDR mission.** The committee should identify its unique niche in disability, rehabilitation, and independent living research, and ensure that its efforts benefit its many stakeholders and partners. Initiatives should focus on the interagency nature of the ICDR and complement the work that agencies are already doing. Establishing a consistent, trusted brand would help achieve its mission.
- 2. Clarify roles and expectations.** Clearly established expectations are needed for each agency partner to ensure buy-in and support. As the ICDR pursues its collective work it must consider and respect the diversity of agency missions, perspectives, priorities, and decisions. Agencies should be accountable for fulfilling their roles. Committee members should be clear on what decisions they are empowered to make and share that information with fellow members.
- 3. Establish collaborative, lasting working relationships.** Committee members must trust their partners for mutual efforts to be most effective. Commitment to the ICDR's mission is critical and membership can be encouraged and supported by actively soliciting diverse perspectives, positions, and opinions.

4. **Prioritize and focus on shared priorities and essential activities.** Identifying realistic and meaningful activities will help develop common ground among members, capitalize on existing capabilities and leverage resources. This will assist in decision-making about what can be realistically accomplished with the time and resources available.
5. **Ensure communications and activities are transparent.** Communication should be open and regular among committee members and across agencies. ICDR goals, strategies, and activities should be transparent with agency contributions openly recognized.
6. **Document positive impacts.** Success will be determined by measuring the positive impacts that disability research and collaboration have on the disability community. The ICDR should pursue clearly defined goals that are compelling and meaningful to member agencies, demonstrate accountability, and share concrete outcomes.

Scope of the ICDR

The scope of disability, independent living, and rehabilitation research is broad. It includes many types of research: epidemiology, economics, health services, translational, and program evaluation, among others. It addresses physical and cognitive function, rehabilitative services, technology, social and community integration, and independent living. It spans all types of disabilities including physical, cognitive, psychiatric, sensory, communication, and chronic conditions that result in functional limitations.

The ICDR believes that high quality research and development is essential to improving the quality of life of people with disabilities. There is great value in generating new knowledge. The ICDR recognizes the complex interactions among research, policy, and practice. Research-based evidence can be applied to solve disability policy and program problems and to address societal and environmental conditions. Conversely, disability policy and practice can inform the direction and nature of research.

Strategic Planning Process

The ICDR embarked on a year-long planning process to develop the strategic plan. The ICDR Executive Committee (EC), composed of 17 statutory member agencies and invited agency representatives, served as the decision-making body for the strategic planning process. One of the first activities, and a part of the mandated activities required by WIOA, was to set the vision and guiding principles for success. The EC decided to concentrate on the interagency nature of the ICDR and focus on areas that complement what agencies are already doing, while being responsive to priorities in the research and disability communities.

The charge to develop this plan is complex and multi-faceted. Some of its mandated components are discreet tasks that have been successfully completed. Others will require the prioritization of multiple agency partners and significant resources, both human and financial. These, and other challenges, have historically been identified when attempting to unify government investments and priorities in the area of disability, independent living, and rehabilitation research.

The strategic plan also builds upon previous efforts to promote interagency collaboration and increase the impact of the ICDR. These efforts include:

- Focused efforts in FY 2013-2014 to increase federal agency awareness of disability and rehabilitation research and related activities across the federal government. The partnership meetings highlighted the need for the ICDR to facilitate connections and partnerships between federal agencies and across the disability and rehabilitation research community.
- [*Creating a Sustainable Interagency Coordination Network on Disability Research: Report of the Expert Panel*](#) includes findings and recommendations of an ICDR Expert Panel that met in FY 2014 to identify the state of the science related to interagency collaboration and suggest steps toward creating a sustainable interagency coordination network around disability research.
- [*Primer on Interagency Research Collaboration*](#) serves as a reference guide that includes an overview of best practices to foster interagency collaboration based on an ICDR literature review, documents from other interagency research efforts, and the ICDR expert panel report.

After considering the recommendations and lessons learned, the ICDR reviewed other federal strategic planning efforts. The EC adopted the process they would use to develop the government wide strategic plan in August 2015.

Barriers and Opportunities

The Expert Panel identified barriers to disability research collaboration that may affect the success of this plan including:

- Limited success in engaging active participation by key federal statutory members;
- The need for a stronger foundation for federal agencies to share information and collaborate on disability research;
- A lack of funding to support disability research and the infrastructure and initiatives of the ICDR;
- Ability to balance the broad scope of the ICDR with the need to be pragmatic in what can be successfully accomplished; and
- The need to engage more stakeholders in the ICDR and disability research.

Through this government wide strategic plan, the ICDR hopes to capitalize on synergies and opportunities including:

- Plans to leverage efforts and resources between the government wide strategic plan and other related federal initiatives, advisory committees, and planning efforts, including the National Institutes of Health Medical Rehabilitation Coordinating Committee (that authored the NIH Rehabilitation Research Plan), the Interagency Autism Coordinating Committee, The Federal Interagency Traumatic Brain Injury informatics system Research, Interagency Pain Research Coordinating Committee, President’s Committee for People with Intellectual Disabilities, Interagency Collaborative to Advance Research in Epilepsy, and others. A list of federal interagency disability initiatives is included in the supplemental document, [Federal Disability Initiatives](#).
- The opportunity created by the requirement for the GWI to harmonize understanding and definitions among agencies about what disability, independent living, and rehabilitation research includes. The ICDR needs to consider the differing needs of people with intellectual, social, sensory, physical and psychiatric disabilities. In addition, some individuals, such as people with autism and cerebral palsy need habilitative services to gain functioning. These discussions will be important, not only as the ICDR considers its scope of research, but in designing the GWI.

Working Groups

Five topical working groups of the ICDR convened to define critical research problems that included more than 100 representatives of federal, research, service provider, and advocacy organizations. According to the WIOA charge, the key content areas for the ICDR to address include assistive technology (AT) and universal design (UD), education, employment, health, rehabilitation, wellness, independent living, community integration and participation. Five working groups addressed these topics and generated a list of research gaps and opportunities. They refined those suggestions into topics, and solicited further stakeholder input to articulate priorities and recommendations that include underemphasized areas of research. This information informed strategic planning deliberations and is found in the supplemental document [Working Group Research Gaps, Problem Statements, and Final Priorities](#).

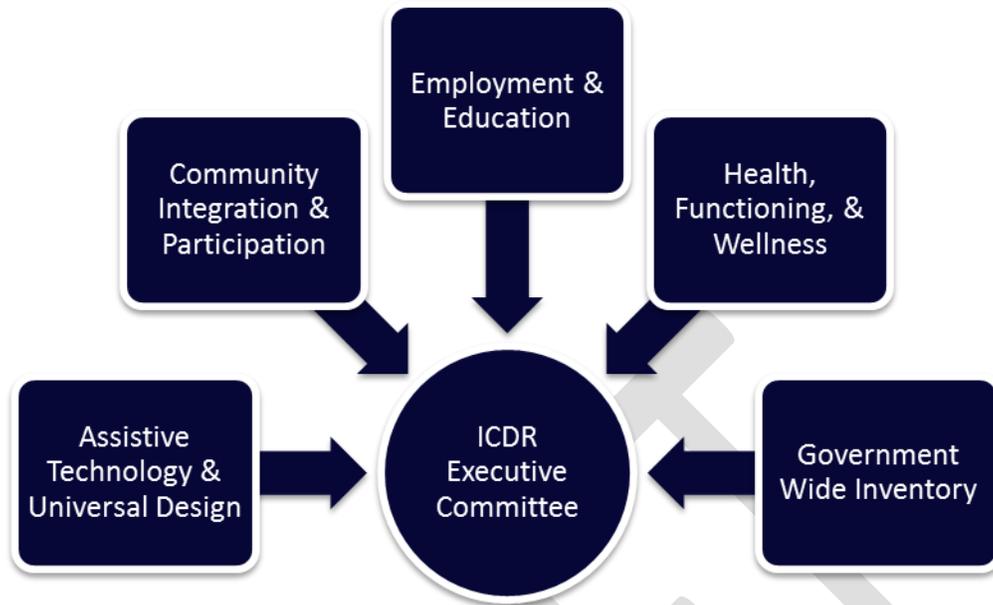


Figure 2: ICDR Working Groups

- The **Assistive Technology and Universal Design (AT/UD)** working group scope includes research, design, development, policy, systems, and services related to AT, accessibility of electronic information and technology, products, and environments.
- The **Community Integration and Participation (CIP)** working group scope includes research, policy, systems, and services related to behavioral, social, and environmental factors affecting inclusion in society.
- The **Employment and Education (EE)** working group scope includes research, policy, systems, and services related to employment and self-sufficiency of people with disabilities; and youth transition to employment, post-secondary education, and community life.
- The **Government Wide Inventory (GWI)** working group is charged with developing the WIOA-mandated GWI of disability, independent living, and rehabilitation research.
- The **Health, Functioning, and Wellness (HFW)** working group scope includes research, clinical, translational, policy, systems, and services related to medical rehabilitation, prevention, health and wellness care, public health issues, and surveillance. This group initially focused primarily on health and wellness. An additional medical rehabilitation research stakeholder input session suggested the addition of “functioning” to the title of this working group.

Stakeholder Input

Stakeholders were involved in the strategic planning process from the start. Consistent with WIOA, stakeholders include:

- Policymakers
- Representatives from other federal agencies conducting relevant research
- Individuals with disabilities
- Organizations representing individuals with disabilities
- Researchers
- Providers

Stakeholders were actively engaged in the working groups. Additionally, the ICDR held two stakeholder webinars in November 2015 to encourage further stakeholder input. A second stakeholder webinar in March 2016, welcomed stakeholder review and comment on the strategic plan framework and cross-cutting themes. After receiving this stakeholder input, the ICDR held three more meetings to obtain additional stakeholder input on the medical rehabilitation aspects of disability, independent living, and rehabilitation research. A supplemental document, [Working Group Research Gaps, Problem Statements, and Final Priorities](#) contains the full set of stakeholder ideas and working documents generated in the strategic plan development process.

Strategic Goals and Objectives

Over the last year, the ICDR has worked to identify the processes and tasks needed to operationalize certain parts of the strategic plan. This plan incorporates those recommended processes and future actions (including goals and objectives, where possible) to honor both the letter and spirit of WIOA. To be successful, the government wide strategic plan must be an iterative document, requiring the ongoing commitment of all federal agencies conducting relevant research in the targeted areas.

To maximize the likelihood of success, the ICDR designed this first government wide strategic plan to focus on a short timeframe – one to three years. The plan highlights both research related and process related goals and objectives. Working groups forwarded their prioritized research related goals and objectives. The ICDR leadership and EC selected objectives of interest to multiple government agencies with short-term opportunities to make significant advances. Process oriented goals are directly tied to WIOA mandates for this plan.

Working groups, in multiple meetings, extensively discussed and debated research needs and priorities. The working group co-chairs conceptualized those needs into problem statements and polled stakeholders about their priorities. Working groups also inventoried additional research topic areas and questions. These can be found in the supplemental document [Working Group Research Gaps, Problem Statements, and Final Priorities](#). The EC will continue to revisit the wealth of information gathered through this process as key elements of the goals and objectives outlined below are detailed and completed.

Goal 1: Improve interagency coordination and collaboration in four thematic research areas -- transition, economics of disability, accessibility, and disparities.

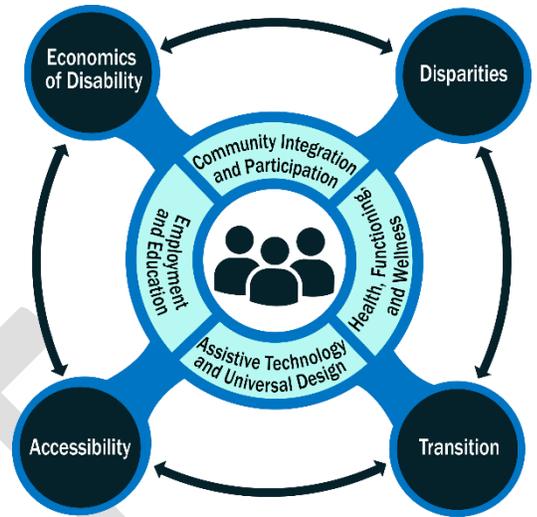
Research can help address many needs in the disability community. For this strategic plan, the ICDR has created a framework to focus the coordination efforts of the ICDR over the next three years. The framework is derived from the extensive stakeholder input and the leadership of the EC. The main content areas identified in WIOA are covered by the five working groups. These groups will focus their activities along four cross-cutting themes: transition, economics of disability, accessibility, and disparities. The thematic approach is designed to stimulate sharing and leveraging of research knowledge in new and creative ways in order to identify research gaps and opportunities for coordination and collaboration among agencies traditionally focused on different topics. The following are some of the areas that may be potentially examined by the working groups in a cross-cutting manner:

- **Transition** (moving from one program, place, or status to another) can be challenging for people with disabilities and is a key concern in many service delivery systems. Research is being conducted on transition issues in different content areas, including scale up models related to education transitions, as well as models for training and educating health care providers in preparing people with disabilities and their caregivers for transitions between providers. By bringing this research together, the ICDR will promote information sharing on models and methods that may more efficiently advance the research in each area, including:

- Transitions in education – school to post-secondary education and community life.
- Transitions in employment – school to work for youth; military to civilian for veterans; career pathways.
- Transitions in health care systems – pediatric to adult care; adult to geriatric care; rehabilitation to primary care; coordination of care between primary and specialty care vital to managing long term disabilities and chronic conditions.
- Transitions in community living – rebalancing in health care; Olmstead decision implementation.
- Transitions for military personnel and veterans with disabilities.
- Transitions in AT/UD – technology transfer of innovations in AT/UD to mainstream technology.

- **Economics of Disability.** Substantial information exists about the costs associated with many disability and rehabilitation programs, services and technologies. However, a lack of integration of this cost-related information makes it more difficult to compile and utilize economic information for policy decisions. For example, some disability policy decisions might rely on studies expressing results in terms of cost identification, cost savings or a cost-benefit ratio, but other decisions might need research results based on cost-effectiveness analysis. Strategically, ICDR prioritizes social and economic research about the overall economics of disability, with a focus on economic outcomes of intervention programs, toward building an evidence base on those programs that work most effectively. Some of the most important topics in this cross-cutting thematic area include:

- Economic outcomes of health care interventions among persons or populations with disabilities – cost-savings, cost-benefit, cost-effectiveness, or cost utility association with prevention, treatment, habilitation and rehabilitation models, calculated at both the individual and systems levels.
- Economic outcomes of employment interventions – social costs of remaining employed vs. receiving benefits from either the Supplemental Security Income or



Social Security Disability Insurance programs; personal and societal costs and benefits associated with participation in state-based vocational rehabilitation programs.

- Economic outcomes associated with expanding community-living options and opportunities – including participation in long-term services and supports compared to institutionalization; programs supporting “aging in place” among elder Americans; housing voucher programs and housing placements in (Olmstead decision) “least restrictive settings” in communities; participation in housing-related services provided by Centers for Independent Living, which can contribute to increasing efficiency in achieving accessible and affordable housing placements and transitions.
- Economic outcomes associated with AT/UD – expressions of consumer demand for accessible and affordable technologies as a function of need and other factors; impact of providing AT on employment rates, possibly within specific industries; market behavior of individuals and organizations; personal and social costs and benefits associated with providing AT or workplace accommodations that enhance productivity; the net effects on an employer’s efficiency or profitability; social costs and benefits exhibited by community-level universal design strategies, retrofitting or construction.
- **Accessibility** of new technologies, especially information and communication technologies, is key to promoting effective participation in society for people with disabilities and the aging population. Foremost among the jeopardies to inclusion is the much lower rate of adoption and use of the internet by people with disabilities; research is needed to understand the reasons and possible public and private solutions for this. Many services and new technologies move forward without considering accessibility needs, limiting equitable access to these services and products. Too often public accessibility policy must react to technologies that have already entered the market; research aimed at early evaluation of emerging technologies promises to improve industry efficiency in avoiding accessibility barriers in the first place. Domains in which such research is essential include:
 - Accessibility in health – user-centered design in electronic health records (EHRs), personal health records (PHRs), telehealth, kiosks, websites; access to health care tools; lack of privacy standards; physical accessibility of health care facilities, equipment, treatment; and standards.
 - Accessibility in education and employment – AT and accommodations, online training, personalization of information technology (IT) interfaces and content.
 - Accessibility in community living – accessible transportation, housing, banking, educational institutions, shopping, etc.; visitability initiatives.
 - Accessibility in AT/UD – inclusive research methods; user-centered design; human factors research, and information security.
- **Disparities.** Continued disparities hinder access and quality of services for people with disabilities in many programmatic and societal contexts. General research often does

not consider people with disabilities. Examples of potential disparity topics in ICDR content areas include:

- Disparities in health – access to preventive, primary, and rehabilitative care; impact of disparities in health care on education, employment, and community living; inclusion of people with disabilities in the health disparities agenda and participation in research as professional and funded researchers, and as consumers (clinical trials, participatory research), including in both cases the training and development necessary for successful participation.
- Disparities in employment and education – research should be in tune with inclusive social policy that aims at mainstream educational and employment settings.
- Disparities in community living – limited availability/distribution of accessible and affordable housing; identification of CIL effective practices to implement the Olmstead decision.
- Disparities in AT/UD – limited access and reimbursement for AT including expensive technologies that do not scale to affordable general use.

Objective 1: Identify current and planned agency research activities related to thematic framework areas.

To establish the landscape of current and planned research activities related to the four thematic research areas (transition, cost-effectiveness, accessibility, and disparities), the ICDR will plan and conduct a data call to gather information from agencies and interagency disability-related groups (see supplemental document, [Federal Disability Initiatives](#)) supporting research, development, and demonstration projects. The purpose is to broadly characterize the federal portfolio and identify meaningful areas for coordination among agencies.

Strategies: Convene a working group to define the objectives, definition of terms, methods, and analyses of the data call with EC oversight. Implement the data call via contract support. Share and discuss the results with the ICDR membership, with an emphasis on identifying opportunities for interagency partnership and coordination.

Metrics: Publish and disseminate a comprehensive summary of federal agency research activities and priorities related to disability transition, cost-effectiveness, accessibility, and disparities by 2018.

Objective 2: Secure agency commitments for coordination and collaboration in selected thematic areas.

Using the results of the data call, agencies will identify complementary areas of existing research and commit to coordinating their individual efforts on those topics. By analyzing planned activities, agencies can select areas for future collaboration that will lead to enhanced outcomes for all.

Strategies: Survey the ICDR member agencies to identify specific interagency coordination and collaboration opportunities, secure commitments, and complete administrative processes as appropriate.

Metrics: Document interagency coordination and collaboration activities in the ICDR annual report and on the ICDR website by 2019.

To complement the high-level coordination and collaboration planning activities under Objectives 1 and 2, the ICDR will address a limited number of specific research related needs generated by working groups during the planning process. These focus on near term interagency activities and have the potential to produce tangible outcomes.

Objective 3: Promote and establish a repository of research materials and best practices for accessible and usable health information technology (IT).

The Affordable Care Act has spurred development of patient-centered health information technology (IT). Following principles of Universal Design (design for all) and explicitly considering people with disabilities and older adults in the development of health IT systems, could have significant impact on the effectiveness and adoption of health IT systems by people who could benefit the most from them. Designing for these populations puts emphasis on functionalities that might not otherwise be evident, and requires special emphasis on accessibility and usability for all potential users. However, many health IT systems, including mobile “apps,” EHRs, PHRs, telehealth, and kiosks are often not accessible or usable. In 2015, the ICDR-sponsored [Accessibility and Usability in Health IT: A Research and Action Conference to Empower People with Disabilities, Older Adults, and Caregivers](#) found that users, developers, accessibility experts, caregivers, and vendors were unaware of a number of existing resources that can lead to more usable and accessible health IT. It is imperative that research-based information about accessibility and usability standards be made readily available to encourage accessible design of health IT systems and to ensure people with disabilities and older adults are not excluded.

Strategies: The Assistive Technology and Universal Design working group will convene a series of meetings with stakeholders and industry to design, populate, produce, and disseminate a repository of accessible and usable health IT resources to enhance awareness of research-based accessibility practices. The working group will also identify a strategy for updating and keeping the repository current, as the repository can serve as a catalyst for further research and development into accessible and usable health information technology, and serve as a resource for policy in that area.

Metrics: Publicly available repository by 2018.

Objective 4: Develop a focused research plan for Centers for Independent Living (CILs) services to understand their value to the disability community.

CILs, funded by ACL, offer valuable services to people with disabilities at the community level. Under WIOA, CIL services were expanded to address Olmstead implementation and transition of youth with significant disabilities. Nevertheless, more needs to be understood about the net impact of specific types of services and delivery methods used by CILs on behalf of individual clients. A research plan focused on CIL services and outcomes is necessary to identify and share effective practices. As a key local provider, it is important to optimize services and expand the population served by CILs.

Strategies: The Community Integration and Participation working group, which identified this as a top priority, will convene a series of meetings to devise a multi-agency strategy to research the services and outcomes of CILs. This will include examination of past research on CIL management and effective practices, research design, and implementation strategy.

Metrics: CIL research plan by 2018.

Objective 5: Develop a housing research portfolio among agencies who share an interest in research and policy related to housing for individuals with disabilities.

Disability-related housing topics reveal constructive synergies that can occur through ICDR interagency conversations to explore and establish collaborative efforts to understand and impact housing for people with disabilities. For example:

- HUD - Financing, community “visitability” initiatives and home modifications
- DOA - Food insecurity associated with suboptimal housing, “food deserts”
- DOJ - Crime, *Olmstead* and other civil rights enforcement
- DOL - Building a well-trained personal assistance workforce
- DOT - Accessible transportation technologies research
- HHS - Preparedness, satisfaction for CILs’ services on housing
- NCMRR/NIH - Scalable strategies and technologies to monitor outcomes in the home and community

Outcomes related to community integration are directly associated with the availability and quality of housing resources for persons with disabilities. The roundtable will explore how agencies might combine their efforts to develop a research portfolio that might include such topics as methods for investigators to evaluate and measure the characteristics of housing stock at both the community and population levels; understand the extent that discrimination constitutes a barrier to obtaining satisfactory housing; the relationship between housing and community integration; outcomes associated with enforcement of the 1999 Olmstead decision,

toward ensuring that persons with disabilities receive housing and other services in the most integrated setting appropriate to their needs; and surveying persons with disabilities about their degree of need for home modifications, financial assistance for housing, and preferences for specific locations or types of housing units all represent worthwhile investigations within this category of a forthcoming research portfolio.

Strategies: Convene a working group of interested agencies to plan for and host a roundtable discussion to discuss agency priorities and collaborative synergies to develop a research plan.

Metrics: Housing research plan by 2019.

Objective 6: Create a Youth Transition Research Academy to analyze and advance quality research methodologies to improve the transition-related evidence base.

Transition from school to post-secondary education and employment remains challenging for many youth and young adults with disabilities. With significant policy and program efforts driven by WIOA underway, it is essential that good research data be considered in real-world settings. There is a need to develop and identify research, evaluation, and scale-up methodologies that can be used to improve and expand the use of evidence-based policy, practice, programs, and services around transition.

Strategies: The ICDR will convene a Transition Research Academy. The goal of the Academy will be to support the development of an improved transition-related evidence base and effective methods of assessing transition at the system level. The Academy will be comprised of representatives from universities; federal state and local agencies; individuals with disabilities; innovation hubs and training institute leaders, for the purpose of analyzing and advancing quality research and scale-up methodologies in transition to adulthood. The Academy will identify current sources of information about research methodologies in research in transition, make information about those sources publicly available on the ICDR website, and plan the Research Academy Methodologies and Scale-Up Conference to discuss current practices and future developments in the field.

Metrics:

1. Identify existing sources of transition-based research, e.g., research libraries and innovation hubs and develop a list of resources on methodologies for transition related research and evaluation that could be added to the ICDR website: October 2018.
2. Host Transition Research Academy Methodologies and Scale-Up Conference: October 2019.

Objective 7: Convene key stakeholders to develop infusion and inclusion strategies to include persons with disabilities as a target audience among federal agencies conducting health and wellness programs and research initiatives.

Individuals with disabilities experience significant health disparities compared to the non-disabled population. These disparities affect persons who are born with a disability, acquire a disability as the result of an accident or injury, or develop a disability as the result of chronic conditions such as diabetes or harsh environmental conditions such as structural bias and residential segregation. There is ample evidence of barriers to accessing primary, preventive, and specialized care (see [Objective 8](#)) among persons with disabilities. Yet, people with disabilities are infrequently included in health and wellness research and broader public health initiatives, such as tobacco control programs, often do not include persons with disabilities as a target population.

Listening sessions and other activities conducted by the then-named Health and Wellness working group identified many contributors to less than optimal health and aging among persons with disabilities, including the under-examined impact of race, ethnicity, socioeconomic position and type of disability (see supplemental document [Working Group Research Gaps, Problem Statements, and Final Priorities](#)). The newly renamed Health, Functioning, and Wellness working group will focus its efforts on both infusing a disability perspective in current federal health promotion activities (including surveillance, research, and programming), as well as advancing opportunities for medical rehabilitation and related health disparities research (see [Objective 8](#)).

Strategies: By 2018, host a roundtable of federal agencies, conducting health and wellness research and programs, to identify effective strategies for including persons with disabilities as a priority audience or target population and disseminating these strategies.

Metrics:

1. Identify effective policy, programmatic, environmental, and/or cultural accessibility strategies that are being implemented by federal agencies conducting health and wellness programs by 2019.
2. Identify effective policy, programmatic, environmental, and/or cultural accessibility strategies that are being implemented by federal agencies funding health and wellness research by 2019.
3. Disseminate effective strategies on the ICDR website by 2020.

Objective 8: Convene key stakeholders to build upon newly defined and emerging federal agency priorities for medical rehabilitation.

The ICDR conducted teleconferences in March and April 2016 to solicit additional stakeholder input for a more detailed gap analysis related to medical rehabilitation research. These

conversations and requests for email comments resulted in a robust set of problem statements included in the supplemental document, [Working Group Research Gaps, Problem Statements, and Final Priorities](#). The Health, Functioning, and Wellness working group will focus its efforts on medical rehabilitation research.

Strategies: Host a roundtable of federal agencies conducting rehabilitation research to reach a common understanding of current research portfolios and priorities. This should recognize and complement existing federal infrastructure that has a similar goal (e.g., the VA and DoD ongoing review process and reporting framework), but acknowledge that additional federal agencies can benefit from knowledge of these processes. This will be critical in identifying future needs and opportunities for collaboration.

Metrics: Identified gaps and opportunities for collaboration and potential synergies by 2017.

Goal 2: Develop a government wide inventory (GWI) of disability, independent living, and rehabilitation research.

WIOA requires the ICDR to develop and maintain a searchable, GWI of disability, independent living, and rehabilitation research for trend and data analysis across federal agencies. This activity is essential for identifying research gaps, duplication, sharing information, and coordinating efforts to maximize the value of resources in a field that encompasses research across many different federal agencies.

Objective 1: Evaluate the applicability of the Federal RePORTER tool to meet the ICDR GWI requirement.

The Federal RePORTER, hosted by NIH, is an initiative of STAR METRICS® to create a searchable database of scientific awards from federal agencies and make this data available to the public. The system comprises data collected by federal agencies on federal investments at the individual, award, and institutional levels for the purposes of managing awards. It represents a wide collaboration of federal science and technology research funding agencies with a shared vision of making data available on scientific awards from federal agencies to the public. This pre-existing system contains a number of features and searchable capacities, which lends itself to be capable of addressing the WIOA requirements on the GWI charge. Most of the agencies funding disability research have linked their agency-based research project database with the Federal RePORTER. Rather than attempting to create a new platform for data collection across multiple federal agencies in order to develop the GWI, specific to disability research, leveraging this existing platform and database holds promise for an efficient, cost-effective, and most likely sustainable approach.

Strategies: Request ICDR members to provide search terms on disability-related topics for use in assessing the feasibility of the searching and analysis enabling features of Federal RePORTER

to operationally define elements for generating a useful domain-specific GWI database that targets end-users based on common search terms.

Metrics: Report with recommendations for next steps by 2017.

Objective 2: Develop an action plan to establish a protocol for generating the GWI from the Federal RePORTER system.

The ICDR will prepare an action plan to generate the disability-research relevant and domain-specific GWI by using the Federal RePORTER system. The results of the work completed under Objective 1 will be further examined and validated. The ICDR will further engage with the NIH office responsible for the development and maintenance of the system, to provide feedback on the quality and validity of the outputs from the search and test analysis, to facilitate continuous data harmonization across databases, and to allow iterative system improvement and enhancements. The plan will consider broad implementation issues — for example: garnering agency support, clarity of definitions, submission procedures, maintenance procedures, and analytic capability.

Strategies: Convene a working group to prepare an action plan. Work with the EC to secure review and approval.

Metrics: Publish action plan by 2018.

Objective 3: Implement and test protocols to generate the new GWI through the Federal RePORTER system.

The ICDR will implement the action plan prepared under Objective 2. Extensive coordination with agencies will be needed to iteratively test and enhance the system used to generate the GWI.

Strategies: Prepare requests for agency participation to continue to periodically provide search terms to the ICDR and maintain collaboration in the Federal RePORTER system to facilitate ICDR's efforts to populate the GWI. Coordinate a series of tests by ICDR members to assess the accuracy and validity of the content and search outputs. Revise and update the system as needed.

Metrics: Make selected outputs from the GWI resource and information pertaining to using the Federal RePORTER available to targeted end-users by 2019.

Goal 3: Promote ongoing stakeholder input on gaps and priorities for disability, independent living, and rehabilitation research.

Stakeholder perspectives on research needs offer critical information to guide the federal research agenda. WIOA requires the ICDR to collect input from policymakers, representatives from other federal agencies conducting relevant research, individuals with disabilities, organizations representing individuals with disabilities, researchers, and providers at least every two years. To promote the use of broad stakeholder input by all federal agencies, a central source of stakeholder input can inform individual agency planning and enhance coordination among agencies. Ultimately, more effective use of stakeholder input will lead to the support of research that meets identified needs in the disability community.

Objective 1: Assess agency need for disability stakeholder input.

To determine an effective way to gather and share disability stakeholder input with relevant federal agencies, it is important to examine how agencies currently collect and use stakeholder input and identify any areas for improvement.

Strategies: Inventory ICDR member agencies on current strategies to collect and use disability stakeholder input and challenges they experience in collecting and applying such input. Identify other potential sources of stakeholder needs information such as journal publications, organization policy statements, and social media discussion sites.

Metrics: Report summarizing results of agency inventory and external resources available by 2018.

Objective 2: Develop action plan to create a central resource for stakeholder input.

Based on the report, the ICDR will consider options for gathering and sharing stakeholder input. For example, options may be to share agency information via the ICDR website, organize formal stakeholder events (hearings, webinars, written testimony) that support multiple agency needs, utilize distributive models of dissemination, or create a crowd sourcing site for ongoing informal stakeholder discussion.

Strategies: Convene a working group to develop an action plan for an easy to use and current resource of stakeholder input that can inform the planning of individual agency research agendas as well as collaborative activities. Present to EC for review.

Metrics: Publish action plan by 2017.

Objective 3: Implement stakeholder input resource in accord with action plan.

Establish and maintain stakeholder input resource.

Strategies: Convene a working group to monitor implementation of action plan.

Metrics: Establish stakeholder resource by 2018.

DRAFT

Appendix A: Authorizing Legislation

Rehabilitation Act of 1973 as amended by the Workforce Innovation and Opportunity Act (WIOA) (Public Law 113-128)

Title 29 – Labor; Chapter 16 – Vocational Rehabilitation and other Rehabilitation Services; Subchapter II – Research and Training

§763. Interagency Committee

Retrieved from

<http://uscode.house.gov/view.xhtml?hl=false&edition=prelim&req=granuleid%3AUSC-prelim-title29-section763&num=0&saved=|Z3JhbnVsZWlkOIVTQy1wcmVsaW0tdGI0bGUyOS1zZWNoaW9uNzYy|||0|false|prelim#amendmnt-note>

(a) Establishment; membership; meetings

(1) In order to promote coordination and cooperation among Federal departments and agencies conducting disability, independent living, and rehabilitation research programs, including programs relating to assistive technology research and research that incorporates the principles of universal design, there is established within the Federal Government an Interagency Committee on Disability Research (hereinafter in this section referred to as the "Committee"), chaired by the Secretary, or the Secretary's designee, and comprised of such members as the President may designate, including the following (or their designees): the Director, the Commissioner of the Rehabilitation Services Administration, the Assistant Secretary for Special Education and Rehabilitative Services, the Assistant Secretary of Labor for Disability Employment Policy, the Secretary of Defense, the Administrator of the Administration for Community Living, the Secretary of Education, the Secretary of Veterans Affairs, the Director of the National Institutes of Health, the Director of the National Institute of Mental Health, the Administrator of the National Aeronautics and Space Administration, the Secretary of Transportation, the Assistant Secretary of the Interior for Indian Affairs, the Director of the Indian Health Service, the Director of the National Science Foundation and the Administrator of the Small Business Administration.

(2) The Committee shall meet not less than four times each year, and for not less than 1 of such meetings at least every 2 years, the Committee shall invite policymakers, representatives from other Federal agencies conducting relevant research, individuals with disabilities, organizations representing individuals with disabilities, researchers, and providers, to offer input on the Committee's work, including the development and implementation of the strategic plan required under subsection (c).

(b) Duties

(1) After receiving input individuals ¹ with disabilities, the Committee shall identify, assess, and seek to coordinate all Federal programs, activities, and projects, and plans for such programs, activities, and projects with respect to the conduct of research (including assistive technology research and research that incorporates the principles of universal design) related to independent living and rehabilitation of individuals with disabilities.

(2) In carrying out its duties with respect to the conduct of Federal research (including assistive technology research and research that incorporates the principles of universal design) related to rehabilitation of individuals with disabilities, the Committee shall-

(A) share information regarding the range of assistive technology research, independent living research, and research that incorporates the principles of universal design, that is being carried out by members of the Committee and other Federal departments and organizations;

(B) identify, and make efforts to address, gaps in assistive technology research, independent living research, and research that incorporates the principles of universal design that are not being adequately addressed;

(C) identify, and establish, clear research priorities related to assistive technology research and research that incorporates the principles of universal design for the Federal Government;

(D) promote interagency collaboration and joint research activities relating to assistive technology research, independent living research, and research that incorporates the principles of universal design at the Federal level, and reduce unnecessary duplication of effort regarding these types of research within the Federal Government; and

(E) optimize the productivity of Committee members through resource sharing and other cost-saving activities, related to assistive technology research, independent living research, and research that incorporates the principles of universal design.

(c) Strategic plan

(1) The Committee shall develop a comprehensive government wide strategic plan for disability, independent living, and rehabilitation research.

(2) The strategic plan shall include, at a minimum-

(A) a description of the-

(i) measurable goals and objectives;

(ii) existing resources each agency will devote to carrying out the plan;

(iii) timetables for completing the projects outlined in the plan; and

(iv) assignment of responsible individuals and agencies for carrying out the research activities;

(B) research priorities and recommendations;

(C) a description of how funds from each agency will be combined, as appropriate, for projects administered among Federal agencies, and how such funds will be administered;

(D) the development and ongoing maintenance of a searchable government wide inventory of disability, independent living, and rehabilitation research for trend and data analysis across Federal agencies;

(E) guiding principles, policies, and procedures, consistent with the best research practices available, for conducting and administering disability, independent living, and rehabilitation research across Federal agencies; and

(F) a summary of underemphasized and duplicative areas of research.

(3) The strategic plan described in this subsection shall be submitted to the President and the Committee on Health, Education, Labor, and Pensions of the Senate and the Committee on Education and the Workforce of the House of Representatives.

(d) Annual report

Not later than December 31 of each year, the Committee shall prepare and submit, to the President and to the Committee on Education and the Workforce of the House of Representatives and the Committee on Health, Education, Labor, and Pensions of the Senate, a report that-

(1) describes the progress of the Committee in fulfilling the duties described in subsections (b) and (c), and including specifically for subsection (c)-

(A) a report of the progress made in implementing the strategic plan, including progress toward implementing the elements described in subsection (c)(2)(A); and

(B) detailed budget information.²

(2) makes such recommendations as the Committee determines to be appropriate with respect to coordination of policy and development of objectives and priorities for all Federal programs relating to the conduct of research (including assistive technology research and research that incorporates the principles of universal design) related to rehabilitation of individuals with disabilities; and

(3) describes the activities that the Committee recommended to be funded through grants, contracts, cooperative agreements, and other mechanisms, for assistive technology research and development and research and development that incorporates the principles of universal design.

(e) Definitions

In this section-

(1) the terms "assistive technology" and "universal design" have the meanings given the terms in section 3002 of this title; and

(2) the term "independent living", used in connection with research, means research on issues and topics related to attaining maximum self-sufficiency and function by individuals with disabilities, including research on assistive technology and universal design, employment, education, health and wellness, and community integration and participation.

(Pub. L. 93-112, title II, §203, as added [Pub. L. 105-220, title IV, §405, Aug. 7, 1998, 112 Stat. 1173](#); amended [Pub. L. 105-277, div. A, §101\(f\) \[title VIII, §401\(16\)\], Oct. 21, 1998, 112 Stat. 2681-337, 2681-412](#); [Pub. L. 105-394, title II, §201, Nov. 13, 1998, 112 Stat. 3651](#); [Pub. L. 108-364, §3\(b\)\(1\), Oct. 25, 2004, 118 Stat. 1737](#); Pub. L. 113-128, title IV, §434, July 22, 2014, 128 Stat. 1664.)

Appendix B: About the ICDR

The Interagency Committee on Disability Research (ICDR) was established to promote coordination and cooperation among federal departments and agencies conducting disability, independent living, and rehabilitation research programs including programs relating to assistive technology research and research that incorporates the principles of universal design. The ICDR is charged to:

- identify, assess, and seek to coordinate all federal programs, activities, and projects, and plans for such programs, activities, and projects with respect to the conduct of research (including assistive technology research and research that incorporates the principles of universal design) related to independent living
- obtain input from policymakers, representatives from federal agencies, individuals with disabilities, organizations representing individuals with disabilities, researchers and providers;
- share information about research being carried out by members of the committee and other federal departments and organizations;
- identify and make efforts to address areas of research that are not being adequately addressed;
- identify and establish clear research priorities;
- promote interagency collaboration and joint research activities and reduce unnecessary duplication of effort;
- optimize the productivity of ICDR members through resource sharing and other cost-sharing activities; and
- develop a comprehensive government wide strategic plan for disability, independent living, and rehabilitation research.

The ICDR develops its agenda and establishes goals and objectives through an interagency Executive Committee (EC). The EC is comprised of ICDR statutory member agencies, the ICDR standing committee co-chairs, and other designated agency representatives. In carrying out its duties, the EC:

- sets the ICDR agenda;
- works to promote effective interagency coordination, collaboration, and communication;
- provides guidance to the ICDR committees;
- reviews and approves committee plans;
- secures the input of other federal agencies and other stakeholders;
- develops the ICDR strategic plan; and
- hosts meetings to advance the agenda of federal departments, offices, and partner agencies.

ICDR statutory members include:

- Secretary, Health and Human Services
- Director, National Institute on Disability, Independent Living, and Rehabilitation Research (Designated Chair)
- Commissioner, Rehabilitation Services Administration
- Assistant Secretary, Special Education and Rehabilitative Services
- Assistant Secretary, Labor for Disability Employment Policy
- Secretary, Defense
- Administrator, Administration for Community Living
- Secretary, Education
- Secretary, Veterans Affairs
- Director, National Institutes of Health
- Director, National Institute of Mental Health
- Administrator, National Aeronautics and Space Administration
- Secretary, Transportation
- Assistant Secretary, Interior for Indian Affairs
- Director, Indian Health Service
- Director, National Science Foundation,
- Administrator, Small Business Administration

Some federal partners play key leadership roles on the ICDR by serving as co-chairs for standing committees, providing co-funding for specific activities, and providing resources to help the ICDR achieve its goals.

Appendix C: Definitions

This section contains Definitions from WIOA and Operational Definitions for the working groups and crosscutting themes included in the strategic framework.

Definitions from WIOA

The following are key strategic planning-related terms as specified in the WIOA reauthorization of the ICDR.

Key stakeholders – policymakers, representatives from other federal agencies conducting relevant research, individuals with disabilities, organizations representing individuals with disabilities, researchers, and providers.

ICDR purpose – to promote coordination and cooperation among federal departments and agencies conducting disability, independent living, and rehabilitation research programs including programs relating to assistive technology research and research that incorporates the principles of universal design.

Independent living – used in connection with research, means research on issues and topics related to attaining maximum self-sufficiency and function by individuals with disabilities, including research on assistive technology and universal design, employment, education, health and wellness, and community integration and participation.

Searchable government wide inventory – the ICDR is responsible for the development and ongoing maintenance of a searchable government wide inventory of disability, independent living, and rehabilitation research for trend and data analysis across federal agencies.

Strategic plan – a comprehensive government wide strategic plan for disability, independent living, and rehabilitation research. The strategic plan shall include, at a minimum:

- a description of the
 - measurable goals and objectives;
 - existing resources each agency will devote to carrying out the plan;
 - timetables for completing the projects outlined in the plan; and
 - assignment of responsible individuals and agencies for carrying out the research activities;
- research priorities and recommendations;
- a description of how funds from each agency will be combined, as appropriate, for projects administered among federal agencies, and how such funds will be administered;

- the development and ongoing maintenance of a searchable government wide inventory of disability, independent living, and rehabilitation research for trend and data analysis across federal agencies;
- guiding principles, policies, and procedures, consistent with the best research practices available, for conducting and administering disability, independent living, and rehabilitation research across federal agencies; and
- a summary of underemphasized and duplicative areas of research.

ICDR Operational Definitions

Working Groups

The **Assistive Technology and Universal Design (AT/UD)** working group scope includes research, design, development, policy, systems, and services related to AT, accessibility of electronic information and technology, products, and environments.

The **Community Integration and Participation (CIP)** working group scope includes research, policy, systems, and services related to behavioral, social, and environmental factors affecting inclusion in society.

The **Employment and Education (EE)** working group scope includes research, policy, systems, and services related to employment and self-sufficiency of people with disabilities; and youth transition to employment, post-secondary education, and community life.

The **Government Wide Inventory (GWI)** working group is charged with developing the WIOA-mandated GWI of disability, independent living, and rehabilitation research.

The **Health, Functioning, and Wellness (HFW)** working group scope includes research, clinical, translational, policy, systems, and services related to medical rehabilitation, prevention, health and wellness care, public health issues, surveillance, etc. This group focused primarily on health and wellness. An additional stakeholder input session suggested the addition of “functioning” to the title of this working group.

Cross-Cutting Themes

Transition includes issues of moving from one program, place or status to another.

Economics of disability includes a lack of integration of cost-related information that makes it more difficult to compile and utilize economic information.

Accessibility includes limited use of accessible design in the physical and electronic space.

Disparities includes differences in opportunities and access to services are prevalent in all of the ICDR content areas.