

# WORKING GROUP RESEARCH GAPS, PROBLEM STATEMENTS, AND FINAL PRIORITIES

*A Supplement to the Government Wide Strategic Plan*



INTERAGENCY COMMITTEE ON  
DISABILITY RESEARCH

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# WORKING GROUP RESEARCH GAPS, PROBLEM STATEMENTS, AND FINAL PRIORITIES

## *A Supplement to the Government Wide Strategic Plan*

This supplement compiles the information that the working groups developed and used to propose objectives for the ICDR to consider for the government wide strategic plan. The working groups, brainstormed research gaps and opportunities, then developed problem statements that from the issue areas that emerged during the brainstorming process.

The ICDR selected objectives for the government wide strategic plan based on the following considerations:

- The interagency nature of the ICDR,
- Potential to develop common ground among agencies,
- Ability to capitalize on existing capabilities,
- Opportunities to leverage resources,
- Priorities of the disability community,
- Benefits to stakeholders and partners,
- Opportunities to advance an area,
- Gaps in knowledge, and
- Obstacles to overcome to make progress.

These background materials will be useful as the ICDR implements the working group objectives. The ideas generated may also be useful to other federal disability and research initiatives focused on disability independent living and rehabilitation research.

## **Introduction**

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

Coordinated by the ICDR, the 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 Expert Panel identified the need for the ICDR to focus their initial efforts on “tackling one ‘wicked’ problem at a time through a collaborative implementation process.” ICDR chair,

John Tschida, directed the ICDR to focus on actionable, achievable, and strategic efforts. Based on this direction, in August, 2015, the ICDR Executive Committee (EC) adopted a general framework for narrowing the broad array of issues to a few strategic action initiatives likely to have the greatest impact.

The ICDR invited federal representatives and interested stakeholders to join the working groups and recruited additional participants through outreach to organizations related to disability, rehabilitation, and independent living research, as well as other relevant stakeholders. The ICDR developed strategies and tools for the working groups to utilize to develop their proposed priorities and ultimately, each working group identified and considered possible ICDR issues through slightly different methods.

The general framework is described below. Working group co-chairs adapted the framework based on what they determined would work the best in their particular group. An additional stakeholder input session followed the working group priority setting to focus on medical rehabilitation and followed a similar process:



Figure 1: Strategic Planning Framework

- **Brainstorm Ideas:** The first meetings were to brainstorm ideas for potential issues related to the ICDR mission. The meetings utilized online whiteboard and chat technologies, emails, and teleconferences to generate ideas, and asked participants to follow up with additional ideas after the meeting.
- **Refine Ideas:** To prepare for the second meetings, the co-chairs grouped ideas and developed problem statements for the working groups to consider. The co-chairs and members narrowed the list down to a smaller list of problem statements.
- **Prioritize Ideas:** The working groups discussed and refined the problem statements and proposed some to be considered for stakeholder input.
- **Stakeholder Input:** The ICDR solicited stakeholder input in May 2016.

- **Select Priorities:** Working groups recommended actionable strategies that were accepted by the ICDR.

This supplemental document is a compilation of materials developed by each working group. Though each group had the freedom to adapt the process to meet their needs, each group generally divided the work into the following stages of the process:

- A. **Initial Brainstorming:** Working groups identified and developed research gaps and potential opportunities in a brainstorming process.
- B. **Problem Statements:** Working groups narrowed their focus to a smaller number of issue areas, then selected and/or adapted the highest priority problem statements for further development.
- C. **Proposed Priorities and Action Plans:** Working groups further developed their proposed priorities and developed action plans to present at the ICDR Executive Committee (EC) meeting on January 20, 2016.
- D. **Selected Objectives:** After stakeholder input, the ICDR considered the proposed priorities and actions plans and selected a small, achievable list of objectives to move forward in the government wide strategic plan.

# **Assistive Technology and Universal Design (AT/UD)**

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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.

## ***A. AT/UD: Initial Brainstorming.***

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Federal representatives and interested stakeholders identified potential research areas of interest, research gaps, and potential opportunities related to assistive technology and universal design. Next, they grouped the ideas into topic areas.

1. Accessible Transportation
  - a. Accessibility in education and environment
  - b. New modes of public transportation to support accessibility
  - c. Haptic devices
  - d. Global Public Inclusive Infrastructure (GPII)
2. Accessible Health Information Technology (IT)
  - a. Accessibility standards in health IT
  - b. Integrating ownership and accessibility of health IT
  - c. Having more devices (aside from personal devices) that have built in AT
  - d. Remote logging of data
  - e. “De-medicalizing” of AT
  - f. Using conventional apps, instead of specialized apps
  - g. Tele-health
  - h. Accessible kiosks
  - i. Training designers/developers
  - j. Leveraging current devices to have accessible capacities for health data
3. Accessible Voting
  - a. Accessible Voting Technology Initiative (look into)
  - b. Accessibility features in IT
4. Electrical Sensitivities (Perhaps use this as a topic for the Health and Wellness Working Group)
  - a. Shielding electromagnetic fields
  - b. Electrical pollution/Wi-Fi/radiofrequency sickness
5. Cloud Accessibility
  - a. Clearinghouse for products – developers can test their products with people with disabilities (PWD)
  - b. [NIST Framework for Cloud Accessibility](#)
  - c. GPII
6. Connecting PWD with Universal Design Solutions
  - a. Development and ongoing maintenance of a searchable government wide inventory

- b. Technology training and best practices
- 7. Assistive Technology and Services
  - a. Terminology gap
  - b. Video relay interpreting (VRI)
  - c. Research on quality of life
  - d. Accessible captioning
  - e. Haptic interfaces, design process in mind
  - f. Low literacy technology used for varying populations
  - g. Translation
  - h. Crowdsourcing
  - i. Full accessibility in media
  - j. Tension between security/privacy and accessibility/usability
  - k. Customization in services
- 8. 3-D Printing
- 9. Building Capacity
  - a. Hackathons
  - b. Teaching accessibility to developers (at various levels) and in formal training
  - c. Digital structure, accessible wayfinding
  - d. Best practices for training workforce with disabilities (with current technologies)
  - e. International Association of Accessibility Professionals (IAAP)
  - f. Teaching Accessibility Initiative
  - g. Interdisciplinary teams, working with PWD
  - h. Integrating accessibility and disability into standard curriculum for engineers/developers
  - i. Using PWD as decision makers in AT processes
  - j. Community building with researchers of different disciplines
  - k. Understanding the moral and ethical consequences of AT (education)
  - l. Ensuring end user needs are well represented
- 10. Accessible PDFs (authoring)
  - a. Tools to Identify accessibility; or tools for ease of creating accessible docs
- 11. How to Scale-Up
- 12. Aging
  - a. Smart home technology
  - b. Job retention as workers age
  - c. Praise for universally accessible buildings
- 13. Accessibility for Multiple Factor Authentication
- 14. Translating Research
- 15. Economics
  - a. Social costs of inaccessibility
  - b. Economic research to make the business case for accessibility
  - c. Economics of universal design and AT
- 16. Making Accessibility the Norm

## ***B. AT/UD: Problem Statements.***

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Following the initial brainstorming sessions, the AT/UD working group refined their focus and developed the following problem statements. These were submitted and presented for stakeholder review and comment during two stakeholder webinars.

### **Problem Statement 1: Accessible, Usable, and Interoperable Health Information Technology: Health, Wellness, and Information Access (Potential for Collaboration with Health and Disability ICDR Committee)**

The Affordable Care Act has spurred the development of person-centered health IT. Though a large population of users of health IT is people with disabilities and older adults, many health IT systems, including “apps”, electronic health records (EHRs), personal health records (PHRs), telehealth, and kiosks, are not accessible and/or usable, nor is the industry utilizing current knowledge about universal design. There is a need to research benefits for clinical, home and community-based service delivery systems. There is a need to apply accessibility standards to health IT and introduce vendors to automated testing/evaluation tools. Research is needed on all aspects of accessibility in health IT physical design as well as interface. One expressed need is for the ICDR to promote, sponsor, or assemble a repository of education materials and best practices. This resource could provide examples (back end and front end) of health IT accessible designs.

### **Problem Statement 2: Building Capacity**

Includes research, as well as practice; academia as well as industry. Integrate accessibility and disability into standard curriculum for engineers/developers/designers and health workforce. Create scalable course materials. Promote accessibility hackathons. Follow the newly forming certification program of the International Association of Accessibility Professionals (IAAP). Explore possible certification of VR assessment and intake specialists. Also, develop best practices for training workforce with disabilities. Need to use people with disabilities as decision makers in AT process. Build a Community of Practice with researchers of different disciplines. This area may utilize techniques such a DIY (Do It Yourself), 3-D printing, and crowd-sourcing. This area would involve interesting researchers from diverse fields into accessibility (e.g., computer vision, natural language processing).

### **Problem Statement 3: Economics of Assistive Technology (AT) and Universal Design (UD)**

The working group expressed interest in gathering hard data on the economics of universal design and AT, including policy research and development. It is a branch of the sociology of technology that is needed for sustainability. We need to contemplate the possibility that the quality of life and benefits to consumers may be great, but comes at a price to consumers, providers, and taxpayers. We need to counter current misinformation about the cost of accessibility with data that shows real costs and real benefits. Show that it is beneficial to incorporate accessibility at the start of design rather than introduce AT at the end of development. Economic research is needed to make business case for accessibility. Consider tax incentives for providing accessibility. Consider universal design in housing. Stress the aging

population and how the demand for accessibility will increase. Document the positive feedback loop of improved accessibility in overall customer experience. Consider the total social cost of inaccessibility.

### ***C. AT/UD: Proposed Plans and Priorities.***

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The following are a compilation of the proposed strategic plan priorities and action plans that the AT/UD developed and presented to the EC based on the multi-step strategic planning process.

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#### **AT/UD-1: Economics of Assistive Technology (AT) and Universal Design (UD)**

##### **Goal**

Assess the value of assistive and accessible technologies in employment and to manufacturers. Consider the rising population of older adults.

##### **Problem Statement**

There is a lack of evidence-based research on the costs and benefits of universal design and assistive technology. Demographic information is needed to show how the need for accessibility increases with our rising aging population. Specifically, there is a need for research that supports a business case for accessibility, and the value of tax incentives. There is also a need for research that shows the benefit of incorporating accessibility early into a product development lifecycle.

##### **Background**

There is some information available to support web accessibility. However, there is also a need for research on information and communications technology (ICT) hardware and software. As a federal entity, ICDR can lead by shining a spotlight on the issue. We could gather a state of the science on the issue. We can help set priorities for future research on the issue. We need to be prepared to accept that there is *some* degree of cost with accessibility, but that does not mean it is an undue burden. We need to focus by narrowing the cluster of issues to specific discussion questions. For example, showing the demand for accessibility and assistive technology by older adults is different from clarifying the cost of inaccessibility. It is important to include older adults and people with disabilities in the research.

## Desired Outcomes

<b>Desired, Measurable, Short-Term Outcomes</b> (can be formative or summative)
<ul style="list-style-type: none"> <li>• Literature search</li> <li>• Interviews with Rehabilitation Engineering Resource Centers (RERCs), manufacturers and procurement officials</li> <li>• Contact companies who have already embraced accessibility.</li> <li>• Identify research already accomplished in this area of user adoption of assistive and accessible technologies</li> </ul>
<b>Desired, Measurable, Long-Term Outcomes</b> (can be formative or summative)
<ul style="list-style-type: none"> <li>• Improved technology accessibility in employment for people with disabilities.</li> <li>• Improved technology accessibility in services to the public.</li> <li>• Increased awareness among employers and aging professionals about accessible and assistive technologies.</li> <li>• Increased use of ICT accessibility features by older people.</li> <li>• Demonstrated evidence that A/AT helps people sustain employment and live independently.</li> <li>• Identification of costs and benefits of federal 508 and 255 regulations on the industry.</li> <li>• Determination of the value of accessible and assistive technology to the industry “bottom line.”</li> <li>• Development of solid data that advocates can present to employers and companies that do business with the public to encourage them to embrace assistive and accessible technologies.</li> </ul>

## Measurable Objectives

Measurable Objectives	By when?	Responsible Agencies
Review the literature on this topic	2017	TBD
Summarize the literature	2017	TBD
Interview Area Agencies on aging, RERCs, manufacturers (small and large companies), procurement officials, and industry associations: CEA, ITI, TIA, CTIA.	2017	TBD
Summarize interviews	2017	TBD
Plan and host a conference	2018	TBD

## Required Resources

- ICDR contractors to perform literature search and help coordinate summit
- Potential support
- Access Board can provide meeting room for summit

## Potential Support (Agency, personnel, etc.)

- NIDILRR
- Access Board
- DOL
- DOT
- NCHS

## Other Background/Information Links

- <http://www.w3.org/WAI/bcase/Overview.html>
- <http://www.peatworks.org/content/accessibility-making-business-case-employers>
- <http://www.ssbartgroup.com/reference/whitepapers/accessibility-business-case/>

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## AT/UD-2: Accessible and Usable Health Information Technology: Health, Wellness, and Information Access

### Goal

Accessible and Usable Health Information Technology: Health, Wellness, and Information Access

### Problem Statement

The Affordable Care Act has spurred the development of patient-centered health information technology (IT). Though a large population of users of health IT is people with disabilities and older adults, many health IT systems, including “apps”, EHRs, PHRs, telehealth, and kiosks, are not accessible and/or usable nor is the industry utilizing current knowledge about universal design. There is a need to apply accessibility standards to health IT and introduce vendors to automated testing/evaluation tools. Research is needed on all aspects of accessibility in health IT. One expressed need is for ICDR to promote, sponsor, or assemble a repository of education materials and best practices. This resource could provide examples (back end and front end) of health IT accessible designs.

### Background

Here health IT is very broadly defined to include not only EHR/PHR but also wearables, kiosks, intelligent adapted exercise equipment, sensors (such as in homes/facilities to detect falls/important health events, electronic “coaches” (to assist in activities of daily living – for example). Health and healthcare is a national priority very much under discussion. The importance of person-centered healthcare is clear, and the triple aim of ONC (improved patient care, reduced cost, and improved health outcomes) is being fleshed out. It is imperative that

people with disabilities and older adults not be ignored as they are the “super users” who stand to have the greatest benefit from any kind of health IT.

It is also clear that this area requires cooperation and coordination of research/development efforts across the government. It requires attention from the “main stream” and efforts from the “disability and older adult” sectors in order to be successful. ICDR can play a uniting role in the “disability and older adult” sectors which will help to raise the awareness from the “main stream” sectors.

There are many funding streams and internal government efforts that are related to this topic that might be used to bolster this effort. Several of these were tapped for the Accessible Health IT Conference held in September 2016 (see link below). Here are a few (in addition to what NIDILRR is funding):

- CMS Testing Experience and Functional Tools (TEFT) in Medicaid community-based long term services & supports (LTSS) Planning and Demonstration Grant Program (Contact Michael Smith)
- NSF Smart and Connected Health Program (Contact Wendy Nilsen)
- Several funding streams from AHRQ (Contact Tiffani Bright)

Other agencies who have interest and work in the area:

- NIH Dissemination and Implementation in Health Study Section
- Department of Veterans Affairs
- Department of Justice (Disability Rights Section)
- Office of the National Coordinator of Health Information Technology (Policy section)
- Centers for Medicare and Medicaid Services

This problem statement could encompass several others brought up in the previous ICDR executive committee meeting including:

- Health Preventive Services
- Public Health and Surveillance
- Health Disparities and Interventions for Persons with Disabilities

And could be a positive influencer on:

- Healthcare Access and Quality
- Longitudinal Data Collection on Targeted Populations

## Desired Outcomes

<b>Desired, Measurable, Short-Term Outcomes</b> (can be formative or summative)
<ul style="list-style-type: none"> <li>• Literature search</li> <li>• Compilation of tools/resources from the Accessible Health IT conference</li> <li>• Convening of meetings/discussions/working groups involving the affected parties</li> </ul>
<b>Desired, Measurable, Long-Term Outcomes</b> (can be formative or summative)
<ul style="list-style-type: none"> <li>• Mention of accessibility and usability (in particular for people with disabilities and older adults) in “main stream” health IT discussion</li> </ul>

## Measurable Objectives

Measurable Objectives	By when?	Responsible Agencies
Initial framework/organizational scheme set up for the collected resources	TBD	NIDILR, Access Board, CMS, NSF, NIH, VA, DOJ, ONC, CMS
Population of scheme with resources from the AHIT conference (as a web resource)	TBD	NIDILR, Access Board, CMS, NSF, NIH, VA, DOJ, ONC, CMS
Convening of meetings/discussions	TBD	NIDILR, Access Board, CMS, NSF, NIH, VA, DOJ, ONC, CMS

## Required Resources

- ICDR contractors to begin and implement initial resources uncovered in AHIT conference (with some oversight).
- Time and personnel resources from the agencies involved for discussions and work toward the desired outcomes.

## Other Background/Information Links

- <http://icdr.acl.gov/AHIT/index.html> - This is the home page for the AHIT Conference. When the proceedings document is up, it will be a valuable resource. In the meantime, the agenda, presentations, and speaker bios are all very useful documents.
- <http://www.rectech.org/> - Information on accessible exercise equipment.

## *D. AT/UD: Selected Objective.*

The following objective was selected to include in the final version of the government wide strategic plan.

**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 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 of further research and development into accessible and usable health information technology, and serve as a resource for policy in that area.

# Community Integration and Participation (CIP)

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

## A. *CIP: Initial Brainstorming.*

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Federal representatives and interested stakeholders submitted written suggestions of potential research areas of interest, research gaps, and potential opportunities related to Community Integration and Participation. The CIP compiled and organized all submitted input into a few main topical areas.

1. Housing - First Ingredient for Community Integration
  - a. The estimated state-level housing need coming from Olmstead, state rebalancing efforts, and meeting the needs of individuals with disabilities to live in the most integrated settings over the next 5 to 10 years?
  - b. Share of the estimated need expected to include very-low income households who might require rental housing assistance to live in the community?
  - c. Size of units needed to meet the housing need of these households (one, two, three-bedroom units)
  - d. Types of properties or developments required to respond to this need, such as small group homes, permanent supportive housing, or individual rental units
  - e. Preferences or needs relative to the location of these properties (central urban, suburban, or rural areas)
  - f. Percentage of units are expected to require certain accessibility features of the unit or the neighborhood, such as wheelchair accessible units, hearing/visual accessible units, extra room for a living aid, access to public transportation, and support with activities of daily living and/or instrumental activities of daily living
  - g. Whether housing needs vary by disability type and/or special long-term services and supports needs
  - h. The role of housing usability in need for personal assistance services, level of community participation and health outcomes.
2. Longitudinal Data Collection on Targeted Populations
  - a. Development and deployment of consistent IDD-related measures and data collection processes across federal agencies, programs, and surveys.
  - b. Implementation of a longitudinal data system that follows a cohort of people with IDD over their lifespan, within and outside of the public service systems, capturing an array of quality of life outcomes that include and extend beyond education, employment, economics, self-determination, community integration, health, and social connectedness and inclusion.
  - c. Outcome measures related to community living and participation that have sound psychometric properties and can be used by provider organizations and

- states to measure outcomes of programs that support people with IDD to live and participate in their community. These measures should include operationalization of constructs such as self-determination, social inclusion, participation and employment that have been difficult to develop and measure in a person centered way.
- d. Early and consistent employment opportunities for youth with disabilities that hold promise for increasing health and quality of life over the life course. Conduct longitudinal research on the impact of early employment.
  - e. Longitudinal data collection on outcomes linked to self-determination, participation, health, and employment and the factors that influence outcomes
  - f. Policies or strategies that might facilitate increased linkages between various providers so that vulnerable populations receive timely assistance with as little burden as possible.
  - g. Policies or strategies that can help simplify knowledge of available services across multiple entry points
  - h. Research to identify changes in policies or new strategies that decrease burden for vulnerable populations that require assistance to maximize community participation
  - i. How to “push” knowledge gained more quickly into the community, particularly to providers with minimal knowledge of the needs of individuals with disabilities
3. Efficacy of Interventions Designed to Improve Community Integration and Participation
    - a. Identification and clear articulation of the benefits, outcomes and challenges of community living and participation as compared to congregate, segregated, and population-specific living.
    - b. Studies related to
      - i. Impact of Centers for Independent Living (CIL)
      - ii. Housing development
      - iii. Accreditation
      - iv. Best practices in independent living
      - v. Transitional costs savings
      - vi. Employment
      - vii. Social media
      - viii. Technology and independent living
    - c. Accessible, consumer-friendly, and effective intervention models to empower consumers to take responsibility for their own wellness and prevention strategies to optimize their health.
    - d. Research on the development and efficacy of interventions.
    - e. Implementation research on the factors that support and impede implementation of evidence-based interventions across different context.
    - f. Ways to promote greater involvement and participation on the part of people with disabilities in decision-making. Supported Decision Making has potential to

do this, but there is a need for systematic intervention research to show how people can fully participate in decisions that affect their lives.

- g. Effects of independent living services on specified consumer outcomes (e.g., independence, full community participation, health, ethic of civic service)
  - h. Policy research to address this and other federal policy deterrents to increased employment and improved health in order to improve full community participation for people with disabilities. Research has demonstrated that employment is a health determinant and that the ability to accumulate assets above usual federal Medicaid limits is associated with better health and quality of life for people with disabilities.
4. Methods for Scaling Up Community-Level Interventions with Demonstrated Efficacy
- a. Strategies to scale up evidence based effective interventions designed to promote community living and participation. Create strategies to implement these strategies in community environments (vs. disability specific organizations).
5. Optimizing Community Integration and Participation Outcomes through Managed Care Services
- a. The effectiveness of public service systems to facilitate employment and to advance systems changes that most effectively bolster employment and decrease reliance on public benefits.
  - b. The impact of managed care on the quality of life and inclusion of people with disabilities. More and more states are putting out contracts for private managed care companies to manage the Medicaid services offered by states to members who are aged or who have blindness or other disabilities.
  - c. Managed care services done well, should lead to improved home and community based services, better access to long term services and supports (LTSS) enabling people with disabilities to live in the community. It is unclear whether these supports would lead to increased employment. The theory is if people have the health care they need, and access to LTSS, then they are better able to pursue a job in mainstream employment. Such a study might also identify needed changes to Medicaid so people with disabilities, who need LTSS (i.e., attendants) can keep those attendants and through a buy in, go to work, pay taxes and leave poverty behind.
  - d. Integrated and consumer-directed models of comprehensive care coordination: Models for effective care coordination involving self-determination and consumer empowerment have been proposed but not tested across a range of types of disabilities and ages of persons with disabilities. Test care coordination models that place decision-making power in the hands of the consumer, and that reach across agencies, funding sources, and formal and informal support sources. This would include developing models that would optimize supports available under managed care systems.

- e. Development of a health-community health environment checklist tool to support access to health care—with special attention toward disability and aging
- 6. Evaluation of Outcomes Associated with Services Provided by Centers for Independent Living
  - a. A more complete understanding of the barriers and facilitators to community participation and effective programs and services that enhance the community participation and inclusion of individuals with psychiatric disabilities.
  - b. The effects of secondary health conditions on community living for people with severe disabilities including the risk and protective factors for disruption for continuity of community living and effective interventions.
- 7. Traumatic Brain Injury as a Chronic Condition
  - a. Establish the prevalence of TBI among persons with disability
  - b. How to predict the likelihood of executive function weaknesses from lifetime history of TBI
  - c. Development of an understanding of the contribution of lifetime history of TBI and resulting executive function weaknesses to problems in community integration
  - d. Types of brain injuries increase risk for negative outcomes
  - e. Pre-existing conditions that require management?
  - f. Prevention and early detection of conditions that develop post-injury
  - g. Effective participation in self-management
  - h. How access to medical and rehabilitation care might reduce negative outcomes
  - i. How access to community-based resources improve function and reduce institutionalization
- 8. Barriers Associated with Consumers' Receipt of Medicaid Long Term Services and Supports (LTSS)
  - a. Status and trends in LTSS
  - b. People with disabilities not in formal LTSS
  - c. Personnel for LTSS (including family caregivers)
  - d. Outcomes of Managed LTSS
  - e. How and whether coverage available through Medicaid expansion and through the marketplaces meets the health care needs of people with a variety of disabilities and might break the chain of dependence on federal disability benefits that are the only gateway to comprehensive insurance coverage for many people with disabilities
  - f. Feedback on how hard or easy it is under Medicaid to recruit and maintain home healthcare providers and how that impacts quality of life and community involvement

## ***B. CIP: Problem Statements.***

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Following the initial brainstorming activities, the Community Integration and Participation working group refined their focus and developed the following problem statements. These

were submitted and presented for stakeholder review and comment during two stakeholder webinars.

### **Problem Statement 1: Housing - First Ingredient for Community Integration**

Outcomes related to community integration are directly associated with the availability and quality of housing resources for persons with disabilities. How might investigators evaluate and measure the characteristics of housing stocks at both community and population levels? To what degree does discrimination constitute a barrier to obtaining satisfactory housing?

Developing a research portfolio on the relationship between housing and community integration should induce the resources and cooperative participation of the Department of Housing and Urban Development, Office of Policy Development and Research. Investigating 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, should induce the involvement of the Department of Justice, Office of Civil Rights. 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.

### **Problem Statement 2: Longitudinal Data Collection on Targeted Populations**

Very little is understood about whether system-level interventions among persons with intellectual or psychiatric disabilities or traumatic brain injury actually generate any beneficial effects on self-determination, social inclusion, participation, quality of life, or employment. Such constructs and outcomes are difficult to quantify. Evaluating such outcomes generally requires data derived from longitudinal observations of individuals or a cohort who receive either formal, informal, or no support services. For example, persons having sustained TBIs earlier in their lives are apparently enjoying longer lifespans while continuing to experience the effects of their injury. In many ways, long-term survival from TBI now imitates life lived with a chronic disease such as cancer or diabetes.

It might be worthwhile to expand existing research programs focusing on TBI from the foundational viewpoint of the direct effects of such injuries on the brain, cognition and personality, into a broader viewpoint that investigates the effect of living with TBI on individuals within a community, and in that community itself. Research related to longitudinal data collection among persons with intellectual or psychiatric disabilities would incorporate investigation into “best practices” or methods for identifying and following specific persons with specific types of disabilities. Such methods would have to address persons who are both enrolled in formal service delivery systems, as well as those who receive either informal or no services and who therefore might be difficult to track and follow longitudinally, but whose experiences contribute to overall community-level outcomes. Nevertheless, convening and maintaining a true longitudinal cohort of such persons would be expensive and difficult; enrollment in another large-scale federally-sponsored longitudinal cohort, the National Children’s Study, had to be closed in 2014 because of cost overruns. Therefore, research on the

longitudinal benefits of community integration might emphasize alternate statistical approaches, such as modeling community-level inputs and outputs among members of a “virtual cohort.”

### **Problem Statement 3: Methods for Scaling Up Community-Level Interventions with Demonstrated Efficacy**

The results from several decades of NIDRR-sponsored research, particularly generated by the RRTC and RERC programs, have been very impressive in demonstrating the usefulness and general efficacy of interventions or programmatic initiatives, but generally only among individual clients or small cohorts of study participants. Very little is understood about the differential effects of specifically targeting of interventions to or among individuals, health care practitioners or disability service providers, or at the community at-large, and whether combining targeted interventions yields greater effects than one intervention alone. In the new era represented by specifically incorporating “Independent Living” concepts into NIDILRR’s mission, rather than testing or demonstrating previously-evaluated interventions at the cohort level, it might be worthwhile and necessary to test and demonstrate methods for scaling up those cohort-level interventions that might work best or generate the most favorable outcomes at the community level. It will be important to identify and measure the most efficient strategies for scaling up small-bore interventions into large-caliber community interventions.

For example, research results recently generated by one RRTC demonstrated that persons with disabilities who are employed respond with high degree of sensitivity to the specific characteristics of coverage within their employer-sponsored health insurance packages, even inducing “job mobility” or job changes among such employees seeking to maximize their health insurance benefits. How could these effects be similarly demonstrated at the national or population level? Could interventions targeting large numbers of employees with disabilities, such as awareness about health insurance coverage gaps, change employer or employee behaviors, be associated with improved outcomes in community integration? “Scaling up” is broader than simply increasing service volume or inputs to accommodate a larger number of clients. Instead, scaling up requires understanding community dynamics, the differential presence of barriers and facilitators in each community, and priorities expressed by persons with disabilities in specific types of communities, such as rural communities.

### **Problem Statement 4: Evaluation of Outcomes Associated with Services Provided by Centers for Independent Living**

Few can question the intrinsic value of services offered by Centers for Independent Living (CILs), nor their role in bolstering disability rights and self-determination. Nevertheless, little is understood about the net impact of specific types of services and delivery methods utilized by CILs on behalf of individual patients and clients when assessed at the community level. What does work at CILs? What does not work well at CILs? Should services with only a low level of demonstrated efficacy be provided by CILs optionally or according to client preference? What is the untapped potential of CILs to deliver health and social services not adequately delivered by other types of personnel or agencies?

As with any business organization or entity, it would be worthwhile to clarify those management practices that enhance the operation of CILs, which are highly-specialized business organizations offering services for both hidden and visible clients. How might CILs better induce clients who had not previously participated in CIL programs to enter the facility and receive optimized services? If clients express satisfaction with the receipt of specific services, such as job coaching, housing assistance, or legal counseling, how can such services be streamlined in order to provide them for a larger proportion of clients within a community?

**Problem Statement 5: Optimizing Community Integration and Participation Outcomes through Managed Care Services and Barriers Associated with Consumers' Receipt of Medicaid Long Term Services and Supports**

During the last decade, Congress has debated whether to require the states to expand their Medicaid-sponsored Long-Term Services and Supports (LTSS) programs. Although generally supportable in theory, expanding LTSS programs presents many practical difficulties. For example, states have an incentive to deliver LTSS programs on a contractual basis, often through managed care companies which quantify each capitated service they deliver but without paying attention to the longer-term negative or positive outcomes of delivering such a service at the community level. Managed care systems have a reputation for delivering services at only the minimum level, such that a worthwhile line of investigation would be into the detrimental effects of managed care systems on outcomes associated with health, employment, or community integration. Then, there might be beneficial aspects or outcomes associated with delivering health and social services in managed care environments, which might contribute over time to improvements in community integration and peoples' degree of participation in their communities. Additionally, among persons with some types of disabilities, for example intellectual disabilities, and among the states, there can be broad differences in the types or intensities of LTSS services delivered, and unfortunately a lot of variability in the depth and quality of data collected and reported about services and outcomes. Investigating this problematic breadth or even divergence of types of LTSS provided by the states would be very important and timely. Improving data quality and accessibility to transparent data about LTSS services provided would be of paramount interest.

How might managed care systems be engineered to deliver the potentially beneficial outcomes, without delivering undesirable or unsatisfactory outcomes, particularly when evaluated at the level of communities? At the level of the community or population, it would be important to support investigations into the delivery and receipt of specific types of services typically offered by managed care providers or schemes. For example, providing an assigned, qualified personal care assistant for clients in Medicaid LTSS programs, which are typically delivered by managed care organizations, represents a quantifiable intervention whose effects could be measured. What might be the characteristics of a personal care assistant intervention in the managed care environment that not only enable clients to handle their own hygiene and utilize transportation to get to their job, but also contribute to enhanced quality of life and reductions in poverty?

Methods for estimating the size of unserved or underserved populations would be essential, too, in order to demonstrate that Medicaid LTSS providers are making services available to all potential clients, not just those easily identified by appearing on other types of service rosters.

### *C. CIP: Proposed Plans and Priorities.*

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The following are a compilation of the proposed strategic plan priorities and action plans that the CIP developed and presented to the EC based on the multi-step strategic planning process. The EC considered these and selected an achievable priority to move forward in the draft strategic plan process. These can be found in Goal 1, Objective 4 and Goal 1, Objective 5 of the strategic plan.

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#### **CIP-1: Housing: First Ingredient for Community Integration**

##### **Goal**

Working in partnership with the Department of Housing and Urban Development (HUD), sponsor research initiatives or joint Program Announcements that shed light on the relationship between a person's disability status and their housing options and choices, toward maximizing the number of Americans with disabilities who desire and are able to obtain and remain in suitable, affordable, and accessible housing units in communities, rather than institutions.

##### **Problem Statement**

Outcomes related to community integration are directly associated with the availability and quality of housing resources for persons with disabilities. How might investigators evaluate and measure the characteristics of housing stocks at both community and population levels? To what degree does discrimination constitute a barrier to obtaining satisfactory housing?

##### **Background**

Developing a research portfolio on the relationship between housing and community integration should induce the resources and cooperative participation of the Department of Housing and Urban Development, Office of Policy Development and Research. Investigating 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, should induce the involvement of the Department of Justice, Office of Civil Rights. 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.

## Desired Outcomes

<b>Desired, Measurable, Short-Term Outcomes</b> (can be formative or summative)
<ul style="list-style-type: none"><li>• [Formative] Building on the foundation provided by the NIDILRR-funded Rehabilitation Engineering Research Center on Universal Design (University of Buffalo), establish and widely disseminate a set of standards for “Visit-ability” in American domiciles, including a Model Ordinance requiring minimum standards for accessibility, for use by local jurisdictions that are engaged in constructing or managing public housing stocks with taxpayer funds.</li><li>• [Formative] Compile and disseminate a body of evidence that describes optimal characteristics of housing that enable persons with Serious Mental Illnesses to participate fully in their communities, for example whether subsidized housing vouchers limit persons with SMIs to low-income neighborhoods with few social supports, toward reducing isolation and expanding genuine community integration.</li></ul>
<b>Desired, Measurable, Long-Term Outcomes</b> (can be formative or summative)
<ul style="list-style-type: none"><li>• [Summative] Foster conditions that reduce discrimination in housing opportunities commonly affecting persons with all types of disabilities, but particularly persons who use wheelchairs and persons with deafness, such as awareness-raising, community-level “barn-raising” events that build ramps and add visual cues such as signage throughout a community’s geography, and high-profile partnerships with nonprofit housing organizations such as Habitat for Humanity.</li><li>• [Formative] Engage in partnerships with local and national private-sector developers and home builders that enhance the desirability and reduce the cost of adding Universal Design or “Visit-ability” features into new housing stocks.</li><li>• [Formative] Collaborate with HUD on the American Housing Survey (AHS), potentially sponsoring added modules related to disability status, or gaining ICDR representation on HUD working groups that would be charged with handling the next redesign or future changes in the sampling frame for the AHS.</li></ul>

<p><b>Measurable Objectives</b></p>	<ul style="list-style-type: none"> <li>• Engage a research initiative focused on the <i>distribution</i> of accessible housing throughout the nation, acknowledging that, to the degree that such housing exists collectively, it is mainly located in urban areas, infrequently in suburban or exurban areas where persons might have wider employment or transportation options, and rarely in rural areas.</li> <li>• With partners potentially from CMS, SSA and HUD, generate an initiative focused on “Aging in Place” among elderly Americans, emphasizing the “Visit-ability” concepts mentioned previously.</li> <li>• Prepare an “issues brief” covering the topic of <i>affordability</i> of housing among Americans with disabilities, including such elements as vouchers and subsidized rents, minimum standards or the degree of disability that should induce housing assistance without having to refer to a person’s income level, and interacting with non-governmental volunteer resources or programs such as Meals on Wheels. This “affordability report” would also summarize the national costs of modifying existing homes in ways that reduce barriers and, in turn, augment participation in communities.</li> <li>• With partners from the Department of Agriculture, Economic Research Service, prepare and disseminate another “issues brief” covering the interactive relationships between disability status, housing opportunities, and “Food Security,” namely the characteristics of one’s housing status that enable them to shop for and procure sufficient, nutritious food.</li> </ul>
<p><b>Time Frame</b> (to meet objectives)</p>	<ul style="list-style-type: none"> <li>• “Partnership Development” with HUD would take time, although HUD has already been forthcoming and helpful to ICDR on topics related to the American Housing Survey; plan on engagement over two years’ time before full-fledged projects or products can arise.</li> <li>• “Issues Briefs” might be prepared and cleared for distribution in two years’ time; a formal or informal “Editorial Board” operating under ICDR auspices might plan a series of three or five such “Issues Briefs” related to housing.</li> </ul>

<b>Responsible Persons/Agencies</b>	<ul style="list-style-type: none"> <li>• CMS, HUD and SSA are the natural partners with ICDR on housing topics. One potential area of shared interests on housing policy between CMS and the ICDR would be</li> <li>• Many nonprofit, academic and volunteer sector organizations or entities exist as potential partners with ICDR on housing topics, for example the academic groups already involved with research on Universal Design (e.g., University of Buffalo, North Carolina State University), or volunteer groups such as “<a href="#">Concrete Change</a>” which spearheads local ordinances that require “Visit-ability” standards in newly built public housing.</li> <li>• The interagency “<a href="#">Federal Geographic Data Committee</a>” promotes the coordinated development, use, sharing, and dissemination of geospatial data on a national basis. This physical and virtual committee’s work is spearheaded by its Secretariat, housed within the Department of the Interior and the U.S. Geological Survey.</li> </ul>
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### Required Resources

At the outset or during a two-year phase-in, most of the activities would involve convening joint committees, which would conduct initial meetings or site visits, and compile existing literature to support future research.

### Potential Support (Agency, personnel, etc.)

- HUD would be the “Launch Partner.”
- The Department of Justice, Office of Civil Rights, is responsible for enforcing legal standards associated with the 1999 *Olmstead* decision related to making the “least restrictive settings” available for housing persons with cognitive impairments in their communities. This OCR would also represent a natural partner in league with ICDR.
- Commercial associations, for example organizations of builders and developers, might become partners on the premise that, with our overall aging society, housing options in the “Visit-ability” context present vastly important economic choices for our nation and its governments.

### Other Background/Information Links

1. Re: Problem Statement # 1 on Housing: “Discrimination in the Rental Housing Market Against People Who Are Deaf and People Who Use Wheelchairs”  
[http://www.huduser.gov/portal/publications/fairhsg/hds\\_disability.html](http://www.huduser.gov/portal/publications/fairhsg/hds_disability.html)
2. Re: Problem Statement # 1 on Housing: “A Picture of Disability and Designated Housing”  
<https://www.huduser.gov/portal/publications/mdrt/disability-designatedHousing.html>
3. In its brochure entitled “Visit-ability: An Approach to Universal Design in Housing” (2012), the RERC on Universal Design defined “Visit-ability” as “an affordable, sustainable and inclusive design approach for integrating basic accessibility features into

all newly built homes and housing.” The RERC stipulated that a domicile is “visitable” if it exhibits or meets three basic criteria:

- a. One zero-step entrance on an accessible path of travel;
- b. Doorways that are 32 inches clear throughout the floor plan; and
- c. Basic access to at least a half-bathroom on the main floor, large enough for a person using a wheelchair to enter the bathroom fully and close the door.

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## CIP-2: Community Living Survey Research Lab (CLSR)

### Goal

Development and testing of survey questions for a mock questionnaire on community living for persons with disabilities.

### Background

The results from several decades of NIDRR-sponsored research, particularly generated by the Rehabilitation Research Training Center (RRTC) and RERC programs, have been very impressive in demonstrating the usefulness and general efficacy of interventions or programmatic initiatives, but generally only among individual clients or small cohorts of study participants. Very little is understood about the differential effects of specifically targeting of interventions to or among individuals, health care practitioners or disability service providers, or at the community at-large, and whether combining targeted interventions yields greater effects than one intervention alone. In the new era represented by specifically incorporating “Independent Living” concepts into NIDILRR’s mission, rather than testing or demonstrating previously-evaluated interventions at the cohort level, it might be worthwhile and necessary to test and demonstrate methods for scaling up those cohort-level interventions that might work best or generate the most favorable outcomes at the community level. It will be important to identify and measure the most efficient strategies for scaling up small-bore interventions into large-caliber community interventions.

For example, research results recently generated by one RRTC demonstrated that persons with disabilities who are employed respond with high degree of sensitivity to the specific characteristics of coverage within their employer-sponsored health insurance packages, even inducing “job mobility” or job changes among such employees seeking to maximize their health insurance benefits. How could these effects be similarly demonstrated at the national or population level? Could interventions targeting large numbers of employees with disabilities, such as awareness about health insurance coverage gaps, change employer or employee behaviors, be associated with improved outcomes in community integration? “Scaling up” is broader than simply increasing service volume or inputs to accommodate a larger number of clients. Instead, scaling up requires understanding community dynamics, the differential presence of barriers and facilitators in each community, and priorities expressed by persons with disabilities in specific types of communities, such as rural communities.

### Desired Outcomes

<b>Desired, Measurable, Short-Term Outcomes</b> (can be formative or summative)
<ul style="list-style-type: none"> <li>Review survey literature and survey instruments on community living; convey a meeting of experts and stakeholders; develop a mock questionnaire.</li> </ul>
<b>Desired, Measurable, Long-Term Outcomes</b> (can be formative or summative)
<ul style="list-style-type: none"> <li>Better understanding of what improves access to - and quality of - community living.</li> </ul>

### Measurable Objectives

Measurable Objectives	By when?	Responsible Agencies
Identification of past research about survey based community living (CL) research	12 months	ACL (NIDILRR, IL); CDC (NCHS); CMS
Conduct expert conference on survey based research on CL	18 months	ACL (NIDILRR, IL), CDC (NCHS); CMS
Identification of partners and collaborators committed to CL survey research	24 months	ACL (NIDILRR, IL); CDC (NCHS); CMS
Development of a) research questions; b) a mock questionnaire; c) sampling strategy, and d) data collection for CL survey	30 months	ACL (NIDILRR, IL); CDC (NCHS); CMS
Conduct a pilot study	36 months	ACL (NIDILRR, IL); CDC (NCHS); CMS

### Required Resources

- Meeting space
- Teleconference capability
- Conference support
- Stipends for expert consultants
- Budget for pilot study

### Potential Support (Agency, personnel, etc.)

- ACL (NIDILRR, IL)
- CDC (NCHS)
- CMS

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## CIP-3: Centers for Independent Living Outcomes

### Goal

Development of research project to evaluate provision of services by Centers for Independent Living (CILs).

### Problem Statement

Few can question the intrinsic value of services offered by Centers for Independent Living (CILs), nor their role in bolstering disability rights and self-determination. Nevertheless, little is understood about the net impact of specific types of services and delivery methods utilized by CILs on behalf of individual patients and clients when assessed at the community level. What does work at CILs? What does not work well at CILs? Should services with only a low level of demonstrated efficacy be provided by CILs optionally or according to client preference? What is the untapped potential of CILs to deliver health and social services not adequately delivered by other types of personnel or agencies?

### Background

As with any business organization or entity, it would be worthwhile to clarify those management practices that enhance the operation of CILs, which are highly-specialized business organizations offering services for both hidden and visible clients. How might CILs better induce clients who had not previously participated in CIL programs to enter the facility and receive optimized services? If clients express satisfaction with the receipt of specific services, such as job coaching, housing assistance, or legal counseling, how can such services be streamlined in order to provide them for a larger proportion of clients within a community?

### Desired Outcomes

<b>Desired, Measurable, Short-Term Outcomes</b> (can be formative or summative)
<ul style="list-style-type: none"> <li>Evaluation of Outcomes Associated with Services Provided by Centers for Independent Living</li> </ul>
<b>Desired, Measurable, Long-Term Outcomes</b> (can be formative or summative)
<ul style="list-style-type: none"> <li>Improved Outcomes Associated with Services Provided by Centers for Independent Living</li> </ul>

### Measurable Objectives

Measurable Objectives	By when?	Responsible Agencies
Identification of past research about management of CILs	18 months	ACL (NIDILRR), ED (RSA)
Identification of CIL effective practices to implement Olmstead (Fifth Core)	24 months	ACL (NIDILRR), ED (RSA), CMS
Identification of CIL effective practices to facilitate the transition of youth who are individuals with significant disabilities (Fifth Core)	24 months	ACL (NIDILRR), ED (RSA, OSEP), DOL
Identification of outcome measures for CIL service provision	30 months	ACL (NIDILRR), ED (RSA)
Development of research questions, sampling strategy, and data collection for CIL evaluation	36 months	ACL (NIDILRR), ED (RSA), HHS (CDC)

## Required Resources

- Small meeting space
- Teleconference capability
- Researcher

## Potential Support (Agency, personnel, etc.)

- ACL (NIDILRR)
- CDC

## *D. CIP: Selected Objectives.*

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The following objectives were selected to include in the final version of the government wide strategic plan.

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

CILs 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.

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### **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; and
- 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 stocks at both 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.

## Employment and Education (EE)

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The Employment and Education 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.

### *A. EE: Initial Brainstorming.*

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Federal representatives and interested stakeholders identified potential research areas of interest, research gaps, and potential opportunities related to employment and education. Next they grouped the ideas into topic areas.

1. Research about the education of students with disabilities as it relates to STEM career workforce development.
  - a. STEM education pathways for students with disabilities
  - b. Research on the positive and negative aspects of learning environments of students with disabilities
  - c. Research on barriers faced, and available solutions
2. Research to provide evidence about the barriers students with disabilities experience in education and then as workers (in specific fields).
  - a. Research on the transportation barriers students with disabilities face, especially in regard to rural and urban areas
  - b. Promotion of workplace learning, transition, and planning
  - c. Lack of accessibility in online learning
  - d. Encouragement of making links to work on Adult Basic Education (ABE) and Adult Secondary Education (ASE) access and utilization for continued engagement
3. Improving the employment participation of people with intellectual or developmental disabilities (I/DD) or other individuals with significant disabilities; by ensuring opportunities for competitive integrated employment.
4. Integrating new NIDILRR research findings into the ICDR and this workgroup where applicable.
  - a. Future research in transition and employment such as the value of work experience, early VR involvement, mitigating risk factors, employer perspectives, etc.
5. Integrating the work of RSA's newly established technical assistance (TA) centers into the ICDR and this workgroup where applicable.
6. Expanding the workgroup's focus to include STEM careers to allow for a very broad range of career pathways reflective of the heterogeneity in the population of individuals with disabilities.
7. Organizing government database sharing to create data mines for researchers.
  - a. Collaborating to share administrative, research, evaluation and program transition data
8. Adults and employment

- a. STEM at post-secondary level for PWD
  - b. Focus on job retention
  - c. Research on factors directly relevant to challenges at work (assistive technology and environmental factors (transportation, health, etc.))
  - d. In post-secondary education and related settings, there is an issue with students (varies by IDEA category) not disclosing their disability
9. Student pathways
- a. Need for plain language information for families and youth with disabilities on employment
  - b. Research –based business case package for employers
  - c. Need for seamless integration of career development along with credentialing
10. Study further into program scale-up
- a. Understand how to scale-up in a broad sense.
  - b. Plan for scale at time of design and collect data to barriers then as well. Think about what elements are critical enough to be retained, and what can flux at scale and not damage the intervention

## ***B. EE: Problem Statements.***

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Following the initial brainstorming sessions, the Employment and Education working group refined their focus and developed the following problem statements. These were submitted and presented for stakeholder review and comment during two stakeholder webinars.

### **Problem Statement 1: Transition**

Many students, youth and adults with disabilities continue to face challenges as they transition from school to post-school activities, including post-secondary education and employment. These individuals often have lower graduation rates, lower postsecondary enrollment rates, and higher unemployment rates than peers without disabilities. There is a need for evidence-based practices to guide programs and services for youth and young adults as they transition from the educational system to the workplace. Promising areas for future research include workplace learning, career planning, early vocational rehabilitation involvement, mitigating risk factors, employer perspectives, and disclosure of disability.

### **Problem Statement 2: Development of Evidence-Based Practices and Scale-Up**

Evidence-based practices are only useful if they result in improved outcomes when implemented in real-world settings. Research in disability employment should produce evidence-based practices that are successful at scale-up. Federal priorities in disability research should encourage researchers to: 1) develop evidence-based practices, 2) conduct research in how to bring promising evidence-based practices, interventions, and programs to scale, 3) incorporate principles of implementation science, and 4) plan for scale early in the research design process.

### **Problem Statement 3: Career Pathways and the Participation of Individuals with Disabilities**

Career pathways are an approach to workforce development that increases the number of adult workers in the U.S. who gain industry-recognized and academic credentials necessary to work in jobs that are in-demand. Career pathways structure intentional connections among employers, adult basic education, support service providers, occupational training, and postsecondary education programs. There are many career pathways efforts underway with limited information on how to study career pathway participants with disabilities.

### *C. EE: Proposed Plans and Priorities.*

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The following are a compilation of the proposed strategic plan priorities and action plans that the EE working group developed and presented to the EC based on the multi-step strategic planning process. The EC considered these and selected an achievable priority to move forward in the draft strategic plan process. These can be found in Goal 1, Objective 5 the strategic plan.

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#### **EE-1: Building and Utilizing the Evidence-Base in Youth Transition**

##### **Goal**

To create a Transition Research Academy for the purpose of analyzing and advancing quality research methodologies. The Transition Research Academy will involve partnering with universities; Federal state and local agencies; individuals with disabilities; innovation hubs and training institute leaders, to support the development of an improved transition-related evidence base and effective methods of assessing transition at the system level.

##### **Problem Statement**

Many students, youth and adults with disabilities continue to face challenges as they transition from school to post-school activities, including post-secondary education and employment. 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, practices, programs and services for youth and young adults as they transition from the educational system to the workplace or postsecondary education.

##### **Background**

Evidence-based practices are useful only if they result in improved outcomes when implemented in real-world settings. Research in transition should produce evidence-based practices that are successful at scale-up. Federal priorities in disability research should encourage researchers to: 1) identify, develop, and analyze research and evaluation methodologies relating to evidence-based policy, practices, services, and programs in transition, 2) conduct research in how to bring promising and evidence-based practices, interventions, and programs to scale, 3) incorporate principles of implementation science, and 4) plan for scale early in the research design process.

##### **\*Current federal initiatives:**

##### **1. Workforce Innovation and Opportunity Act (WIOA)**

<https://www.congress.gov/bill/113th-congress/house-bill/803/text>

*WIOA has a strong emphasis on improving youth transition services, including cross-agency collaboration, the commitment of funds for such services, and the alignment of evaluation standards across program. Importance includes, but is not limited to, the: (1) provision of services to youth with disabilities, emphasizing the need for youth with disabilities to have more opportunities to practice and improve their workplace skills, to consider their career interest, and to get real world work experiences; (2) “Pre-employment transition services” be available to all students with disabilities thus requiring State VR agencies to set aside at least 15 percent of their Federal VR program funds to provide pre-employment transition services to assist students with disabilities make the transition from secondary school to postsecondary education programs and competitive integrated employment; (3) results through the establishment of common employment outcome measures across core WIOA programs, including the VR program in order to promote increased transparency about the outcomes of Federal workforce programs; and (4) common outcome measures across core WIOA programs will allow policymakers, program users, and consumers to better understand the value and effectiveness of the services.*

- 2. Promoting Readiness of Minors in Supplemental Security Income (PROMISE):** a collaboration among the Departments of Education, Labor, Health and Human Services and the Social Security Administration (<http://www2.ed.gov/about/inits/ed/promise/index.html#about>)

*PROMISE was created to foster improved health, education, and post-secondary outcomes for children ages 14-16 who receive Supplemental Security Income (SSI), as well as their families. The primary focus of the initiative is to support improved coordination of various services provided by the relevant Departments. PROMISE also seeks to facilitate the increased use of such services, ensuring that families are tied into programs for which they might be eligible, but are not yet participating. PROMISE goals include the use of rigorous evaluation methods.*

- 3. National Technical Assistance Center on Transition (NTACT):** funded by the Office of Special Education Programs, and the Rehabilitation Services Administration, both of the Department of Education) (<http://www.transitionta.org/>)

*NTACT’s purpose is to assist State Education Agencies, Local Education Agencies, State VR agencies, and VR service providers in implementing evidence-based and promising practices ensuring students with disabilities, including those with significant disabilities, graduate prepared for success in postsecondary education and employment.*

- 4. Federal Partners in Transition (FPT)**

*The Federal Partners in Transition (FPT), a workgroup with representatives of several federal agencies, including the Departments of Education, Health and Human Services, and Labor, and the Social Security Administration, was formed in 2005 to support all youth, including youth with disabilities, in successfully transitioning from school to adulthood. The group’s most recent product is a strategic plan for improving inter-*

agency collaboration in facilitating those outcomes. The plan can be found at:  
<http://youth.gov/feature-article/federal-partners-transition>

- 5. The National Collaborative on Workforce and Disability for Youth (NCWD/Youth):** funded by a grant from the U.S. Department of Labor's Office of Disability Employment Policy (ODEP)

*The National Collaborative on Workforce and Disability for Youth (NCWD/Youth) assists state and local workforce development systems to better serve all youth, including youth with disabilities and other disconnected youth. The NCWD/Youth, created in 2001, is composed of partners with expertise in education, youth development, disability, employment, workforce development and family issues. NCWD/Youth offers a range of technical assistance services to state and local workforce investment boards, youth councils and other workforce development system youth programs.*

- 6. The Disability Employment Initiative (DEI):** funded by the U.S Department of Labor

*The DEI was funded by the U.S. Department of Labor (DOL), Employment and Training Administration (ETA) and Office of Disability Employment Policy (ODEP) in 2010. DEI was designed to improve educational, training and employment opportunities and outcomes of youth and adults with disabilities who are unemployed, underemployed and/or receiving Social Security Disability Income (SSDI), by refining and expanding already identified successful public workforce strategies; improving coordination and collaboration among employment and training and asset development programs implemented at state and local levels, including the expansion of the public workforce investment system's capacity to serve as Ticket to Work (TTW) Employment Networks (ENs) under the Social Security Administration's (SSA) TTW Program; and build effective community partnerships that leverage public and private resources to better serve individuals with disabilities and improve employment outcomes. Thirty-one grants in Rounds 1-4 were awarded from September 2010 to September 2014 to state government agencies which distributed the funds to their local workforce investment areas' (LWIAs) American Job Centers (AJCs) to implement these activities.*

*\*Please note that none of the current federal initiatives listed above focus on improving research or evaluation methodologies in transition. However, they do include the use of evaluation and evidence-based practices to improve transition services, programs, and outcomes. These initiatives, and others like them, would benefit from the action plan we propose.*

## Desired Outcomes

<b>Desired, Measurable, Short-Term Outcomes</b> (can be formative or summative)
<ul style="list-style-type: none"> <li>• Identification of research libraries and innovation hubs for the purpose of identifying, developing, and analyzing research and evaluation methodologies relating to evidence-based policy, practices, services, and programs in transition.</li> <li>• Education and Training opportunities related to scaling-up evidence based transition policy, practices, and programs.</li> <li>• Create a research library, under the ICDR website, to serve as a resource on designing methodologies for transition related research and evaluation.</li> </ul>
<b>Desired, Measurable, Long-Term Outcomes</b> (can be formative or summative)
<ul style="list-style-type: none"> <li>• Transition Research Academy for researchers; staff of Federal, state, and agencies; and individuals with disabilities, focusing on: 1) development and identification of innovative research methodologies to build the transition evidence base; 2) bringing promising evidence-based practices, interventions, and programs to scale; 3) incorporating principles of implementation science and 4) assessing the effectiveness of transition policies, practices, services, and programs at the system level</li> <li>• The Transition Research Academy would host a research and scale-up conference providing a venue for:             <ul style="list-style-type: none"> <li>○ Interdisciplinary learning environment embedded in the theory and practice of transitions</li> <li>○ Collaboration between scholars and practitioners</li> <li>○ Combination of critical reflection, systematic analysis and the sharing of practical tools</li> </ul> </li> </ul>

## Measurable Objectives

Measurable Objectives	By when?	Responsible Agencies
Identify current research libraries and innovation hubs.	12 months	TBD
Host Transition Research Academy Research and Scale-Up Conference.	36 months	TBD
Develop a list of resources on designing methodologies for transition related research and evaluation that could be added to the ICDR website.	TBD	TBD

### *D. EE: Selected Objective.*

The following objective was selected to include in the final version of the government wide strategic plan.

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**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.

## Government Wide Inventory (GWI)

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The Government Wide Inventory working group is charged with developing the WIOA-mandated government wide inventory (GWI) of disability, independent living, and rehabilitation research. To meet the WIOA requirement for a searchable GWI, the ICDR formed a Government Wide Inventory working group to study options. Because this task was already defined by the WIOA statute, the working group did not need to follow the same priority-setting process.

The working group began with a comprehensive assessment of the existing research database infrastructures currently available and used by the ICDR member agencies. The information under consideration included the respective disability-relevant program areas across agencies, the content domains of the agency-specific research databases, their searchable interface functionalities, and the associated resources for management/maintenance. The GWI working group also examined the specific features of customized individual small-scale inventory lists currently adopted and used by the Interagency Consortium for Pain Research and by the Interagency Autism Research Coordinating Committee, and the associated resources needed for their ongoing maintenance. In reviewing these information, the GWI working group has recognized that the scope for disability, independent living, and rehabilitation research is relatively broad, with a diversity of specific domains that are distributed among ICDR member agencies. In addition, the existing database systems currently used by individual agencies mostly have well-developed features and utilities that seem to meet the search needs. It became clear that a unified searching interface that can access to all the relevant agency databases would serve our unique purpose. Based on these conditions and the requirements, and taking into the consideration of the needed resource for future ongoing maintenance, the GWI working group recommended that the ICDR capitalize upon and leverage an existing and evolving government wide database searching interface, the [Federal RePORTER](#), as a solution. The GWI working group identifies this system as currently the most feasible and long-term sustainable option.

The Federal RePORTER is a searchable system developed under the initiative of STAR METRICS® during the American Recovery and Reinvestment Act (ARRA) by a consortium led by NIH and NSF, under the auspices of the Office of Science and Technology Policy (OSTP), to create a repository of data and tools useful for assessing the impact of federal research and development (R&D) investments. As a requirement, the system has a unified searching interface capable of accessing to databases of all the participating agencies. Since then, the system has evolved from its Implementation Level I activities (developing uniform, auditable, and standardized measures of the impact of federal science spending on job creation, using data from research institutions' existing database records) to the Level II activities (through the Federal RePORTER tool, developing an open and automated data infrastructure that will enable the documentation and analysis of a subset of the inputs, outputs, and outcomes resulting from federal investments in science). The system leverages existing data already collected by federal agencies on federal investments at the individual and institutional levels for the purposes of managing awards. It has demonstrated its potential for broad collaboration between federal

science and technology funding agencies with a shared vision of developing data infrastructures and products to support evidence-based analyses of the impact of science and technology investment. The goal of the STAR METRICS® project is to utilize existing administrative data from federal agencies and match them with existing research databases on economic, scientific, and social outcomes. Currently, the project information found in Federal RePORTER is drawn from several extant databases — eRA databases, Medline, and PubMed Central—using newly-formed linkages among these disparate data sources.

As of June 2016, almost all the ICDR member agencies with existing developed research project database had added their database to the Federal RePORTER system. The resulting file information is checked for data quality prior to the upload and again after its integration into the system. Federal RePORTER currently refreshes on a regular basis. The most current data is for fiscal year 2015. The Office of Data Analysis Tools and Systems of the Office of Extramural Research at the National Institutes of Health has taken over the administrative responsibility of the system. Guided strategically by a multi-agency represented working group and coordinated by the OSTP, the NIH office oversees the ongoing maintenance of the system, as well as implements its future planned development and enhancements.

With a nearly-complete uploading and inclusion of the relevant databases from ICDR member agencies, the GWI working group initiated, and continues beta testing analyses using the Federal RePORTER to assess a number of searching capabilities and analyzing features. The first focus was to search for information on the research area of “assistive technology” and a few domain-specific topics funded across the federal government. The group is also working with the other working groups to explore the possibility of conducting analyses using the system to support future ICDR strategic planning update process by testing search and analysis functions focusing on identifying potential shared common interests among agencies, and seeking opportunities for capitalizing on existing capabilities or leveraging resources, as well as avoiding or minimizing duplicated efforts. The working group has established communication with the NIH technical staff responsible for the development and ongoing maintenance of the Federal RePORTER, and plans to provide them with regular feedback on the testing search results and user experience, to facilitate data harmonization across different database, and allow further iterative system improvement and enhancement.

The priorities that the Government Wide Inventory working group ultimately included in the government wide strategic plan, can be found in Goal 2, Objectives 1-3 of the strategic plan, and listed below.

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

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The WIOA reauthorization of the ICDR, 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.

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**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.

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**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 database, 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.

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**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.

## Health and Wellness (HW)

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The Health and Wellness 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. The next section on [Medical Rehabilitation Research](#) includes the work of an additional set of stakeholder meetings focused on that topic. That group recommended the addition of “functioning” to the working group name, to become Health, Functioning, and Wellness so the work of both groups is described under that working group name.

### A. *HW: Initial Brainstorming.*

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During the first brainstorming sessions, federal representatives and interested stakeholders identified potential research areas of interest, research gaps, and potential opportunities related to Health and Wellness.

1. Disability and Public Health
  - a. Develop a public health & disability surveillance system for people with disabilities.
  - b. Develop capacity at the state level with state agencies responsible for achieving health equity for individuals with disabilities.
  - c. Examine morbidity and mortality differences between different groups (income, ethnicity) in people with and without disabilities.
  - d. Infuse disability populations into federal initiatives on health and public health consistently and meaningfully. For example, the Surgeon General’s Call to Action on Walking and Walkable Communities does not include the population of people with disabilities in the goals and recommended action steps, but does refer to disability as a negative health outcome to avoid.
  - e. Many researchers have noted the “aging tsunami,” but aging with a (congenital or acquired) disability is an overlooked issue.
  - f. Delaying medical care because of cost is a problem for people with disabilities- what are the policy/program interventions that could address this problem?
2. Wellness
  - a. We have very little preventive provider services directed for persons with disabilities. If we are to promote maximal quality of life, health care services need to focus on preventing the worsening of sequelae for persons with disability, both for children and adults.
  - b. How to make sure that services needed to create a healthy life are studied. For example, gyms that support disability exercise do not exist. Especially in rural areas, people with disabilities have difficulty getting places.
    - i. Presentation from the RERC on disability and exercise:  
<http://www.rectech.org/>.
  - c. Wellness/Disabilities Centers:

- i. Not only disability centers for health care, but disability centers that allow for promotion of life quality and good coping strategies.
    - ii. Disability focused centers could serve as model to provide input. There are disability centers within Association of University Centers on Disabilities working on various issues.
  - d. Smoking, obesity, diabetes, and people with disabilities -- research on prevalence and effective interventions.
  - e. Mental health: we have significant issues with mental health conditions that eventuate in permanent functional disabilities. We should not leave out a focus on mental health.
  - f. Research on health disparities and health interventions needs to focus on subpopulation differences.
  - g. Research is needed to identify and/or develop evidenced-based health transition programs for youth with disabilities.
  - h. More sophisticated research is needed to determine the impact of disparities on negative health outcomes. For example, do lower rates of cancer preventive screening among persons with disabilities result in greater rates of morbidity and mortality?
- 3. Family and Community Issues
  - a. In looking at the model, it is imperative that not only the patient is the focus of our consideration, but also the family.
    - i. Most people with disabilities affect family life as families are heavily involved in management and impact of disabilities.
    - ii. There is opportunity to utilize community outreach workers.
    - iii. Consider not only the caregiver, but also how disability changes family life. For example, I have a family that when child's equipment is in the car the whole family cannot fit, so someone must stay home.
  - b. Support qualitative research that reflects stories of issues that people with disabilities and their families face. Really, a support of mixed methods.
    - i. Translation research can look at best practices into community.
- 4. Health Care Provider Practices
  - a. Cultural competency of disability among health care providers needs to be addressed.
    - i. Dentists and oral health professionals are not trained appropriately to work with vulnerable populations, including those with disabilities.
    - ii. Workforce development might correct some of the disparity-inducing behaviors of providers and public health professionals.
    - iii. Women's health and reproductive health can be a problem for women with disabilities. OB/GYN and FP clinics aren't always equipped for physical disabilities, and aren't always prepared to discuss contraception/sexual health with adults with mental disabilities.

- b. It might be useful to augment secondary data analysis with primary data collection including impacts on sub-populations.
      - i. There has been research on health provider practices, but is usually limited to MEPS and other secondary data rather than directly with providers.
    - c. Focus on oral health, promoting action-focused research rather than documenting disparities.
- 5. Access to Health Care
  - a. Not having access to adaptive equipment (wheelchair, accessible technology devices) is a barrier. Where does that barrier come from?
  - b. Barriers to health care access often manifest as a local problem (inaccessible clinics, health care provider attitudes, transportation, etc.) but there is little research on local approaches to resolving access problems.
  - c. How do we measure the cost as a nation not to successfully care for people with disabilities?
- 6. Research and Funding
  - a. American Community Survey (ACS) disability identifiers in health surveys and surveillance is helpful, but disability is a complex construct. Eliminating additional identifiers/questions is premature and scientifically unsound.
  - b. Research needs to untangle congenital, acquired, and disability derived from chronic conditions. Determining age of onset may help clarify this problem.
  - c. Current postdoctoral training programs supported by NIDILRR are severely under-funded.
- 7. Emerging Issues
  - a. Include multiple chronic conditions, as with many persons with disabilities, as the slide show indicated, a large impact is on MCCs.
  - b. Environmental Sensitivity – both electrical sensitivity and chemical sensitivity. Consider developing an ICDR-inspired interagency committee to address this issue. (Overlaps with issue raised in brainstorming of ICDR technology committee.)

## ***B. HW: Problem Statements.***

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Following the initial brainstorming sessions, the Health and Wellness working group refined their focus and developed the following problem statements. These were submitted and presented for stakeholder review and comment during two stakeholder webinars.

### **Problem Statement 1: Health Preventative Services**

There is limited preventive health care and services to promote optimal health and wellness, and avert worsening of sequelae for children and adults with disabilities. Across the healthcare continuum, integrated approaches are needed to simultaneously address the many risk factors and conditions, as well as the medical, functional and societal limitations including determinants that influences the health and wellbeing of persons with disabilities.

To effectively and equitably address the disparities in the continuum of care, cross-cutting and integrated strategies can include (1) epidemiology and surveillance for early detection and prevention or to inform needed programs, (2) environmental and community approaches to promote health, support healthy behaviors, including wellness centers to promote healthy lifestyles and (3) intervention that reduces barriers to care and improve the effective use of clinical and preventive services for persons with disabilities. This also means increasing full participation in the community, by reasonable modifications of policies, practices, and procedures.

Some additional related examples:

- Health promotion and wellness facilities that facilitate healthy living, optimal functioning and effective coping strategies.
- How to make sure that services needed to create a healthy life are studied. For example, gyms that support disability exercise do not exist. Especially in rural areas, people with disabilities have difficulty getting places.
- Need for behavioral health and mental health services
- Need for evidence-based health transition programs for youth with disabilities
- Research on disparities and health outcomes among persons with disabilities with poorer outcomes

### **Problem Statement 2: Public Health and Surveillance**

There is a need for better surveillance methods or tools in public health to measure and track prevalence of disabilities and untangle congenital, acquired, and disability derived from chronic conditions. The American Community Survey adopted disability identifiers are helpful, however; since disability is a complex construct, additional identifiers are needed to inform research and promote scientifically sound interventions. Public health and policy professionals need to consider initiatives, such as the Healthy People Initiative, the Survey of Income and Program Participation (SIPP) and the Behavioral Risk Factor Surveillance System (BRFSS), that will help reduce disability-related health disparities.

Other related issues:

- Infuse disability populations into federal initiatives on health and public health consistently and meaningfully. For example, the Surgeon General’s Call to Action on Walking and Walkable Communities does not include the population of people with disabilities in the goals and recommended action steps, but does refer to disability as a negative health outcome to avoid.
- Examine morbidity and mortality differences between different groups (income, ethnicity) in people with and without disabilities.
- Many researchers have noted the “aging tsunami,” but aging with a (congenital or acquired) disability is an overlooked issue.
- Address the issue of multiple chronic conditions in persons with disabilities

### **Problem Statement 3: Health Disparities and Interventions for Persons with Disabilities**

Individuals with disabilities experience significant health disparities compared to the non-disabled population. Despite the documented need, the focus on health disparity issues within the disability population is limited and often ignored. Racial/ethnic minority groups experience higher rates of health disparities compared to their non-disabled peers of the same race and ethnicity. Certain sub-types of disabilities contribute more to the disparity depending on the type of variable. Research on health disparities and health interventions needs to focus on subpopulation differences. Categorical, functional, and social approaches to addressing disabilities will have major implications for addressing disparities.

1. Develop capacity at the state level with state agencies responsible for achieving health equity for individuals with disabilities.
2. Adopt a social determinants approach to addressing health disparities. Integrate family and community issues into the intervention framework model.

#### **Problem Statement 4: Health Care Access and Quality**

There is ample evidence of the barriers to healthcare and quality care, experienced by persons with disability. In general, interventions addressing disparities in healthcare and quality for persons with disabilities, fall short of environmental and contextual factors, makes unrealistic assumptions about equity in structural accessibility, access to resources, and cultural sensitivity. This results in reduced participation among persons with disabilities, especially those with multiple chronic conditions.

Some additional related examples:

- Not having access to adaptive equipment (wheelchair, accessible technology devices) is a barrier.
- Delaying medical care because of cost is a problem for people with disabilities- what are the policy/program interventions that could address this problem?
- Barriers to health care access often manifest as a local problem (inaccessible clinics, health care provider attitudes, transportation, etc.) but there is little research on local approaches to resolving access problems.
- Develop a cultural competency model for addressing healthcare
- How do we measure the cost as a nation not to successfully care for people with disabilities?

### ***C. HW: Proposed Plans and Priorities.***

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The following are a compilation of the proposed strategic plan priorities and action plans that the Health and Wellness working group developed and presented to the ICDR based on the multi-step strategic planning process. The ICDR considered these and selected an achievable priority to move forward in the draft strategic plan process. This can be found in Goal 1, Objective 7 in this strategic plan.

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#### **HW-1: Health Disparities and Interventions for Persons with Disabilities**

## **Problem Statement**

Individuals with disabilities experience significant health disparities compared to the non-disabled population. Despite the documented need, the focus on health disparity issues within the disability population is limited and often ignored. Racial/ethnic minority groups experience higher rates of health disparities compared to their non-disabled peers of the same race and ethnicity. Certain sub-types of disabilities contribute more to the disparity depending on the type of variable.

## **Background**

*Why is it important for the ICDR to address this problem or issue?*

Persistence of disparities among persons with disability. A social justice issue.

*What are existing opportunities, including existing federal priorities or initiatives, related to this problem?*

The HHS in collaboration with other agencies are looking at integrating community and population health improvement initiatives addressing the social determinants of health.

Cross-sector collaboration among community development and community health organizations are taking a Collective Impact approach to improve community health by integrating housing, critical health services, and healthy built environments across the nation. The Robert Wood Johnson Foundation's Commission to Build a Healthier Environment is one example of how a broad strategic approach to addressing healthy equity has potential to include multiple players and stakeholders that can and should address many of the problem statements outlined today. Public health, health care, urban/rural planning, education, community development finance, etc., are all coming together to address health equity and disparities at the community and population level.

<http://content.healthaffairs.org/content/33/11/1968.abstract>. What isn't as clear is the extent to which those initiatives are fully integrating disability population needs and addressing disability disparities in those community health and development activities?

## **Other Background/Information Links**

Evaluate the Collective Impact movement and how/if it is being responsive to the needs of people with disabilities at the person and community level. (i.e., accessible housing, transportation, accessible community navigation, commerce and employment opportunity, location of housing and community development projects—Explore whether they connect to the broader community or remain isolated in disparate groups/populations, skills training, etc.) Intervention efficacy studies focused on the inclusive community approach may help address unknown beneficial effects on self-determination, social inclusion, participation, quality of life, community integration, employment, etc.

We need a relatively standardized approach to evaluating access to housing, community participation, and community integration, realizing that there will be differences across communities/situations and types of disability. People with disabilities should oversee design,

delivery, and interpretation of results from these quantitative and qualitative measures. A longitudinal approach would be ideal and could be made more efficient/realistic using concise data collection instruments and the use of rapid, accessible delivery techniques, including social networking, SurveyMonkey, and community health workers.

Support research that combines science and practice and 2) support small grant programs that are easier to access, and that pays for applied research to practice initiatives and attempts to adapt evidence based practices at the local level. We also need to prioritize projects that are participatory action research projects that include PWD.

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## HW-2: Health Care Access and Quality

### **Problem Statement**

There is ample evidence of the barriers to healthcare and quality care, experienced by persons with disability. In general, interventions addressing disparities in healthcare and quality for persons with disabilities, fall short of environmental and contextual factors, makes unrealistic assumptions about equity in structural accessibility, access to resources, and cultural sensitivity. This results in reduced participation among persons with disabilities, especially those with multiple chronic conditions.

### **Background**

*Why is it important for the ICDR to address this problem or issue?*

There are several reasons including addressing the persistent overall poorer health outcomes of persons with disabilities.

- Lack of policy/program interventions within the healthcare system to address healthcare access and quality of care.
- Barriers to health care access often manifest as a local problem (inaccessible clinics, health care provider attitudes, transportation, etc.) but there is little research on local approaches to resolving access problems.
- Lack of a cultural competency model for addressing care for PWD.
- Limited numbers of community health workers, patient navigators and access to interpreters for PWD.
- Persistent poorer health status for persons with disabilities in rural communities.
- Lack of research program in effectiveness, rehabilitation services research, and practice-based evidence research (as well as new interventions) for persons with disabilities. The health care community needs to turn to the rehabilitation (and disability) community about effective use of the health care system and continuum of care for persons with life-long and new onset disabilities. (Instead of "re-inventing" rehabilitation).
- Lack of health promotion and wellness facilities that facilitate healthy living, optimal functioning and effective coping strategies.

- Lack of healthcare services to create a healthy life are studied. For example, gyms that support disability exercise do not exist. Especially in rural areas, people with disabilities have difficulty getting places.
- Lack of quality behavioral health and mental health services for PWD.
- Lack of evidence-based health transition programs for youth with disabilities.
- Lack of research on disparities and health outcomes among persons with disabilities with poorer outcomes.

Lack of a strong research program in effectiveness, rehabilitation services research, and practice-based evidence research (as well as new interventions) for persons with disabilities.

Some additional related examples:

- Not having access to adaptive equipment (wheelchair, accessible technology devices) is a barrier.
- Delaying medical care because of cost is a problem for people with disabilities- what are the policy/program interventions that could address this problem?
- Barriers to health care access often manifest as a local problem (inaccessible clinics, health care provider attitudes, transportation, etc.) but there is little research on local approaches to resolving access problems.
- Develop a cultural competency model for addressing healthcare.
- Address implementation of access to interpreters especially within emergency rooms (ER).
- How do we measure the cost as a nation not to successfully care for people with disabilities?
- Address the poorer health status for persons with disabilities in rural communities.

Strong research program in effectiveness, rehabilitation services research, and practice-based evidence research (as well as new interventions) for persons with disabilities. The health care community needs to turn to the rehabilitation (and disability) community about effective use of the health care system and continuum of care for persons with life-long and new onset disabilities. (Instead of "re-inventing" rehabilitation).

### **Other Background/Information Links**

Adopt a Collective Impact approach to community initiatives and ensure they fully integrate the needs of disability populations. Cross-sector collaboration among community development and community health organizations are taking a Collective Impact approach to improve community health by integrating housing, critical health services, and healthy built environments across the nation. The Robert Wood Johnson Foundation's Commission to Build a Healthier Environment is one example of how a broad strategic approach to addressing healthy equity has potential to include multiple players and stakeholders that can and should address many of the problem statements outlined today. Public health, health care, urban/rural planning, education, community development finance, etc., are all coming together to address health equity and disparities at the community and population level.

<http://content.healthaffairs.org/content/33/11/1968.abstract>. What isn't as clear is the extent to which those initiatives are fully integrating disability population needs and addressing disability disparities in those community health and development activities? Perhaps - evaluate the collective Impact movement and how/if it is being responsive to the needs of people with disabilities at the person and community level. (i.e., accessible housing, transportation, accessible community navigation, commerce and employment opportunity, location of housing and community development projects—do they connect to the broader community or do they isolate disparate groups/populations, skills training, etc.) Intervention efficacy studies focused on the inclusive community approach may help address unknown beneficial effects on self-determination, social inclusion, participation, QOL, community integration, employment, etc.

We need a relatively standardized approach to evaluating access to housing, community participation, and community integration, realizing that there will be differences across communities/situations and types of disability. People with disabilities should oversee design, delivery, and interpretation of results from these quantitative and qualitative measures. A longitudinal approach would be ideal and could be made more efficient/realistic using concise data collection instruments and the use of rapid, accessible delivery techniques, including social networking, SurveyMonkey, and community health workers.

Support research that combines science and practice and 2) support small grant programs that are easier to access, and that pay for applied research to practice initiatives and attempts to adapt evidence based practices at the local level. We also need to prioritize projects that are participatory action research projects that include PWD.

#### *D. HW: Selected Objective.*

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The following objective was selected to include in the final version of the government wide strategic plan.

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#### **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 to including persons with disabilities as a priority audience or target population and disseminate 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.

## Medical Rehabilitation Research

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Following the Health and Wellness brainstorming sessions, ICDR Chair Tschida convened a second set of stakeholder meetings to discuss additional issues more directly related to the WIOA mandate to consider rehabilitation research. This group suggested adding “functioning” to the health and wellness working group’s title. The strategic plan reflects a name change that combines the efforts of the two groups as the Health, Functioning and Wellness working group.

### *A. MRR: Initial Brainstorming.*

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Federal representatives and interested stakeholders identified the following areas of interest, research gaps, and potential opportunities related to medical rehabilitation research.

1. Relationship Between Government Wide Strategic Plan and the NIH Rehabilitation Research Plan
  - a. The sections of the comprehensive government wide strategic plan should be consistent with the Research Plan on Rehabilitation developed by NIH and the Blue Ribbon Panel on Medical Rehabilitation Research at the NIH.
2. Definition of rehabilitation research
  - a. There is a need for a definition of rehabilitation research. The definition should be consistent with the definition proposed by the NIH Blue Ribbon Panel: “The study of mechanisms and interventions that prevent, improve, restore, or replace lost, underdeveloped or deteriorating function where ‘function’ is defined at the level of impairment, activity, and participation according to the WHO-ICF Model.”
3. Health and Functioning
  - a. It was suggested that the working group name of “Health and Wellness” be changed to include “Function,” as this is an important aspect that should be highlighted when looking at overall health and rehabilitation.
  - b. We need to look at functional fitness of people with disabilities as they age, as they work, and seek to remain employed, etc.
  - c. Research is needed on health promotion interventions that are culturally and disability sensitive, and address motivational factors to enhance self-efficacy and self-determination to improve outcomes in self-management behaviors.
  - d. Focus on the system of care. Examine how to use the post-acute model beyond just acute inpatient rehabilitation, and how to tie in various reimbursement systems in the healthcare model in order to improve outcomes and reduce cost.
4. Capacity-building
  - a. There needs to be a greater acceptance of rehabilitation as a key component of health care. Rehabilitation is just as important as preventing injury and treating illness. There should be greater recognition of rehabilitation as a scientific field and the need to support research in this field of science.

- b. An important issue is how to prepare rehabilitation scientists to obtain funding for research. Rehabilitation is a field of science in which the resources available are insufficient to support young investigators to go into the field.
5. Methodological Approaches
- a. There was concern that sufficient funds will never be available to support needed clinical trials or evidence-based research that will demonstrate efficacy. The strategic plan should include ways to increase clinical trials and recognize other available research to ensure that people are in the right settings and receiving the right quality and quantity of care that they need. For example, there is an urgent need for building research networks so that multi-state clinical research can be conducted. Funding is needed to establish these networks and support multi-site rehabilitation trials.
  - b. Implementation science is also another new emerging field, and we need professionals who have the skills to address the science, answer the questions, and move rehabilitation sciences forward. For instance, a practice-based approach could substitute for the lack of randomized controlled trials in medical rehabilitation.
  - c. Recognizing the practice-based evidence approach as a viable approach for determining efficacy would be a major contribution to the field. Internal pressure within government promotes evidence-based practice by funding research with evidence, rather than “exploratory” or “observational” information.
  - d. Model systems need to be addressed, as well as issues regarding sustainability legitimacy of research.
  - e. Appropriate peer review across all federal agencies for rehabilitation-specific research is needed.
  - f. Practice-based evidence approach, rather than the evidence-based practice approach.
6. Translational Science
- a. Determining effectiveness, and the translation of research to delivery of services, is a major issue in the area of rehabilitation and rehabilitation science.
  - b. Evidence-based medicine and evidence-based practice is an important issue to consider. People will not be able to access care unless there is an evidence-base to demonstrate its value. While there is a growing evidence base in rehabilitation, there is still a lack of sufficient, high quality evidence.
  - c. An overarching issue is translating the research into clinical practice, so that the research being done by different agencies around rehabilitation, health, and function, actually translate into clinical care settings.
  - d. The importance of research utilizing patient-reported data to validate clinician-and-investigator-reported data and to ensure a focus on patient-centered research and care, should be emphasized.
7. Collaboration

- a. The strategic plan should consider other initiatives within the federal government.
  - b. NIH is in the process of developing their strategic plan for rehabilitation science, and there might be opportunity for the ICDR to formally participate in their strategic planning process and upcoming conference.
  - c. Buy in from Centers for Medicare and Medicaid Services (CMS) would be needed in order to get insurance companies to agree.
  - d. International comparisons might be needed. There may be international studies with data that can be used in the U.S.
  - e. Research efforts should, to the extent possible, align with the conceptual framework of and make use of the terminology within the WHO International Classification of Functioning.
8. Economics
- a. There is a need to demonstrate how rehabilitation saves the government money in the long run.
  - b. There needs to be a cross-walk between trials and economics.
  - c. Length of stay in medical rehabilitation is a significant limitation for that should be examined. Not only are some people being barred from rehabilitation, but also others are being discharged too soon, therefore they are not receiving adequate care and rehabilitation that will ultimately help improve their functioning. This is not based on scientific metrics/research, but is done just to save money. This increases the significance of their disability as well as burden on families.
  - d. Research is needed to demonstrate the efficacy of longer treatments that increase functionality. Longer periods of rehabilitation decreases cost, supervision, and likelihood that patients will end up back in hospital systems/post-acute care or their health will deteriorate.
  - e. Regarding length of stay - caps on therapy visits are financially driven. Money is going nowhere if the patient must stop rehabilitation before becoming functional.
9. Access to Care/Reimbursement
- a. There is need to provide clinically relevant information for practitioners who find it difficult to receive reimbursement and justify their prescriptions of care with evidence-based practice.
  - b. There is need to understand how rehabilitation interventions and technologies affect functional performance, activity, and participation, particularly for people with multiple chronic conditions. With increased funding for these interventions, scale up is possible for those interventions that provide the greatest value.
  - c. There is a need to examine and understand the importance of access to the full continuum of rehabilitation care and how this access contributes to the overall “value of rehabilitation.”

- d. Protracted studies are needed to examine the impact of rehabilitation on function, not just the impact of rehabilitation interventions. Studying the populations with multiple chronic conditions related to function, and how rehabilitation can affect the functioning and participation of those individuals. The Oncology Care Model from the Centers for Medicare and Medicaid Services (CMS) is an example.

#### 10. Specific Research Topics

- a. Neuropharmacology and neurological rehabilitation and how it may impede or help recovery in various conditions.
- b. New medical interventions (i.e., stem-cell techniques, etc.).
- c. Alterations, body function, physiology and understanding the relationships of chronic conditions and diseases.
- d. Aging, sex, and genetic variability associated with diseases and conditions and how they translate to disabilities.
- e. Clinical research related to patient outcomes, effectiveness and utilization of orthotics and prostheses.
- f. Cognitive prostheses for people with brain injury, etc.
- g. Case management that helps patients and families navigate their care.
- h. Risk factors for complications and conditions that people with disabilities experience.
- i. Telehealth modalities for improving function, patient monitoring wellness, healthcare access, and complication prevention.
- j. Long-term consequences of disability, and the impact of poverty and the social determinants of health. Some of the complications that patients encounter are related to unemployment and/or poverty levels.

#### 11. Other

- a. The Disability and Research Rehabilitation Coalition (DRRC) submitted a draft document that outlined challenges, guiding themes, general and substantive priorities. It also includes recommendations for continuous improvement with progress and benchmarks. One of the major things the DRRC is hearing from its members is the Importance of outcome measures, methodologies, and the distinction between rehabilitation other aspects of health care. It is also important to consider the concept of how you do research – what kind of methodology you use (what’s appropriate, what’s not) and how it translates into guidelines and the delivery of healthcare.
- b. The ICDR should not be too prescriptive in methodology throughout this process. There are many themes that can apply across disabilities. The “how” is important and needs to be said, but the themes are very important to consider. Themes include:
  - i. Considering the continuum: from the onset of disease or disability through life
  - ii. Fostering health and function

- iii. Participation
- c. Another theme suggested was “self-management.” As resources are added to the systems, the committee should also consider resources needed for the people who will be using them.
- d. There was a meeting in August 2015 with the aim to set the national agenda for research, practice, and policy for people with intellectual and developmental disabilities. As a result, there have been articles, briefs, book, etc. that outline the state of science in terms of health disparities and other issues facing people with IDD, as well as goals and suggested research. Information can be found here: [https://aaid.org/news-policy/policy/national-goals-2015#.Vw\\_hBiHxq4F](https://aaid.org/news-policy/policy/national-goals-2015#.Vw_hBiHxq4F).

## ***B. MRR: Problem Statements.***

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Following the initial brainstorming sessions, the working group refined their focus and developed the following problem statements.

### **Problem Statement 1: Health and Functioning**

Focus on the system of care for the post-acute model beyond just acute inpatient rehabilitation. Consider research on health promotion interventions that are culturally and disability sensitive, and address motivational factors to enhance self-efficacy and self-determination to improve outcomes in self-management behaviors. Study the functional fitness of people with disabilities as they age, as they work and seek to remain employed.

### **Problem Statement 2: Capacity Building**

Promote the acceptance of rehabilitation as a key component of health care. Rehabilitation is just as important as preventing injury and treating illness. Press for a greater recognition of rehabilitation as a scientific field and the need to support research in this field of science. Rehabilitation is a field of science with insufficient resources to support young investigators who need support and encouragement to obtain funding to become successful rehabilitation scientists.

### **Problem Statement 3: Translational Science**

Determining effectiveness, and the translation of research to delivery of services, is a major issue in the area of rehabilitation and rehabilitation science. Evidence-based medicine and evidence-based practices are important issues to consider. People will not be able to access care unless there is an evidence-base to demonstrate its value. While there is a growing evidence base in rehabilitation, there is still a lack of sufficient, high quality evidence. An overarching issue is translating the biomedical and basic research into clinical practice, so that the research being done by different agencies around rehabilitation, health and function, translate into clinical care settings. The importance of research utilizing patient-reported data to validate clinician-and-investigator-reported data and to ensure a focus on patient-centered research and care, should be emphasized.

### **Problem Statement 4: Methodological Approaches**

Internal pressure within government promotes evidence-based practice by funding research with evidence, rather than “exploratory” or “observational” information. Funds may never be sufficient to support needed clinical trials or evidence-based research sufficient to demonstrate efficacy to ensure that people are in the right settings and receiving the right quality and quantity of care that they need. Ways to increase clinical trials and recognize other available research methods include: building research networks so that multi-state clinical research can be conducted; implementation science and practice-based approaches as viable alternatives to address the lack of randomized controlled trials in medical rehabilitation; and addressing the sustainability and legitimacy of research. Appropriate peer reviewed rehabilitation-specific research across all federal agencies is needed.

#### **Problem Statement 5: Collaboration**

Consider other initiatives within the federal government such as the NIH strategic plan for rehabilitation science. Identify ways to formally participate in related disability, independent living and rehabilitation research strategic planning processes. An important collaborator will be the Centers for Medicare and Medicaid Services (CMS) who have leverage getting insurance companies to reimburse for needed services. Also, explore international studies with data that can be used in U.S. research efforts and consider making use of the terminology within the WHO International Classification of Functioning.

#### **Problem Statement 6: Economics**

Research is needed to demonstrate the efficacy of longer treatments that increase functionality. Stakeholders posited that longer periods of rehabilitation decreases cost, supervision and likelihood that patients will end up back in hospital systems/post-acute care or their health will deteriorate. The ICDR should assess the cost-effectiveness of rehabilitation services including denial of access to rehabilitation and limitations to length of stay to save money. Stakeholders reported that decisions to deny rehabilitation services or limiting access to these services are financially driven and not based on scientific metrics/research. These decisions can increase the significance of disability as well and burden on families. With increased funding for these interventions, scale up is possible for those interventions that provide the greatest value.

#### **Problem Statement 7: Access to Care/Reimbursement**

Examine and understand the importance of access to the full continuum of rehabilitation care and how this access contributes to the overall “value of rehabilitation.” There is need to provide clinically relevant information for practitioners so that they can be reimbursed and justify their prescriptions of care with evidence-based practice. Expand the understanding of how rehabilitation interventions and technologies effect functional performance, activity and participation, particularly for people with multiple chronic conditions. Studying the populations with multiple chronic conditions related to function, and how rehabilitation can affect the functioning and participation of those individuals. The Oncology Care Model from the Centers for Medicare and Medicaid Services (CMS) is an example.

### *C. MRR: Proposed Plans and Priorities.*

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Propose plans and priorities were not developed based on the medical rehabilitation research. Instead, an objective based on the problem statements above was developed for inclusion in the strategic plan.

### *D. MRR: Selected Objective.*

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The following objective was selected to include in the final version of the government wide strategic plan.

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#### **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 [earlier in this document](#). 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. This will be critical in identifying future needs and opportunities for collaboration.

*Metrics:* Identified gaps and opportunities for collaboration and potential synergies.