



NIDRR LONG RANGE PLAN PUBLIC COMMENTS

**NATIONAL INSTITUTE ON DISABILITY AND REHABILITATION RESEARCH
OFFICE OF SPECIAL EDUCATION AND REHABILITATIVE SERVICES
U.S. DEPARTMENT OF EDUCATION**

NIDRR LONG-RANGE PLAN FOR FISCAL YEARS 2010 THROUGH 2014

The National Institute on Disability and Rehabilitation Research's (NIDRR's) draft Long-Range Plan (LRP), published in the *Federal Register* on Jan. 15, 2009, describes the major activities NIDRR anticipates funding over the stated period of time. The draft was open for comment from Jan. 15 through March 16, 2009 and NIDRR received 103 public comments.

The assistant secretary for Special Education and Rehabilitative Services proposes NIDRR's LRP for fiscal years 2010 through 2014. Pursuant to section 202(h)(1) of the *Rehabilitation Act of 1973*, as amended, the Education Department is required to develop a plan for NIDRR that outlines NIDRR's priorities for rehabilitation research, demonstration projects, training and related activities, and explains the basis for these priorities.

In developing the research agenda in the proposed LRP, NIDRR considered: the legislative mandate for the LRP; consumer goals (as documented, for example, in public input on preparation of this LRP received via e-mail, the Web, and in a national teleconference in response to a notice published in the *Federal Register* and an e-mail solicitation inviting comment on the LRP); and scientific advances documented through state of the science conferences and literature.

The purposes of the proposed LRP are:

1. To describe the broad general principles that will guide NIDRR's policies and use of resources;
2. To establish objectives for research and related activities from which annual research priorities can be formulated; and
3. To describe how NIDRR will operationalize the plan, i.e., the process by which NIDRR establishes annual priorities.

The authority for the Secretary of Education to establish the LRP is contained in section 202(h) of the *Rehabilitation Act of 1973*, as amended (29 U.S.C. 762(h)).

DCN: 286

RECEIVED: 1/22/2009

COMMENT: I write to express concern regarding the proposed NIDRR Long Range Plan (Federal Register, Vol. 10 (74), January 15, 2009). This plan is seriously flawed and ignores the needs of the majority of persons with disability and chronic disease in the U.S. The narrow focus on employment fails to recognize the realities of the disability community. The over-whelming majority of rehabilitation services and rehabilitation related costs in this country are associated with persons 65 years and older. Employment is NOT a realistic (or desired) outcome for this population. The scientific and research data on this issue are clear and incontrovertible. The Plan ignores the fact that the population of persons 65 years and older is increasing dramatically along with the need for prevention and intervention services supported by research; research that should be supported by NIDRR, but will not under the proposed plan. The proposed Long Range plan is an attempt to redirect the resources of NIDRR to a narrow area of focus (employment) that disadvantages the larger disability community. The Long Range plan must be revised to address the needs of ALL persons with disability, their families and caregivers. I urge the leadership at NIDRR to re-instate the focus on health and function and community participation in meaningful way.

CONTRIBUTOR: Kenneth J. Ottenbacher
University of Texas Medical Branch
kottenba@utmb.edu
(409) 747-1637

DCN: 289

RECEIVED: 1/26/2009

COMMENT: Contrary to congressional intent and longstanding policy and practice, the Notice of NIDRR's proposed long range plan materially departs from previous plans by focusing on one category of research (employment) rather than on all three areas of research (health and function, employment and community participation). I hope that NIDRR reconsiders and refocuses its efforts to address all three areas of research and not just focus on employment.

CONTRIBUTOR: Ken Adams, M.D.
Skilled Rehab Specialists, LLC and UT Southwestern Medical School at Dallas
kenadams@skilledrehabspecialists.com

DCN: 290

RECEIVED: 1/26/2009

COMMENT: Thank you for the opportunity to comment. The NIDRR program is well described. Under the sections Managing for Results and Management Strategy:
The deadlines for the Burn Model System and FI programs are quite variable and require potential applicants to scan the Federal Register and then make necessary adjustments. Would it be possible to establish a standard and repeating schedule for these applications?

CONTRIBUTOR: Loren Engrav
University of Washington
engrav@u.washington.edu

DCN: 291

RECEIVED: 1/26/2009

COMMENT: I do not believe this plan serves the disabled community, or the NIDRR research community, well and may even set us back.

In addition to the expressed concerns by the ACRM about the plan deemphasizing health and function, a major historical component of NIDRR research, the new plan's focus on employment is of uncertain value, because we do not know whether such research is likely to be productive. By simply expressing an important need, it does not follow that useful research will result.

To date, in the opinion of many rehabilitation researchers, NIDRR employment research has been of limited value to the disabled community, and there are few signs that this will change, especially in a difficult employment environment. So we may be sacrificing an outstanding research program for one with at best uncertain return.

CONTRIBUTOR: William Zev Rymer, M.D., Ph.D.
Northwestern University
w-rymer@northwestern.edu

DCN: 293

RECEIVED: 2/2/2009

COMMENT: My comments are in regard to Independent Living and Employment Outcomes. These two issues are very important when you are addressing the needs of people with disabilities living on or near reservations. There are limited services and options for these persons. Many times they have to request assistance from agencies some 110 or more miles away. What is needed is for NIDRR and the tribes to work together to provide these needed services on the reservations.

CONTRIBUTOR: Willie Davis
Disability Advocate
sharkwheels@yahoo.com

DCN: 294

RECEIVED: 2/2/2009

COMMENT: The population of people with developmental disabilities is aging in the community. Their caregivers are also aging. Adults with developmental disabilities living in the community have unique challenges that are far more complex than the elderly and those with fewer functional disabilities. They require a distinct research agenda. Focusing on employment will mean that few of the issues that are most important to people with developmental disabilities will be addressed. We have virtually no information to guide us on how to deliver cost-effective medical care to adults with developmental disabilities. We have almost no information on how they can be integrated with social services. We don't have DD specific health care utilization data. We don't have answers to basic clinical questions such as how do we prevent fractures in people with disuse atrophy? We don't have information on how to support family caregivers as they age. How do we train caregivers to care for people with autism and those with dual diagnosis? What are the long-term medical complications that will result from the widespread use of risperdal in children with autism? It is critical that we develop a robust practice-based clinical research agenda combined with health care services and social services research. We need this information as the population of adults with autism increases dramatically, causing a strain on current health care and social service systems. Transition programs have largely been a failure because the system of care people with DD transition into is so underdeveloped. We urgently need to develop the field of Developmental Medicine to accept patients aging out of the pediatric health care system.

CONTRIBUTOR: Clarissa Kripke, M.D., FAAFP
University of California, San Francisco
KripkeC@fcm.ucsf.edu
(415) 476-4641

DCN: 295

RECEIVED: 2/2/2009

COMMENT: Regarding Section II Need for Employment Focus

I can understand the significance of employment and a serious goal of burn rehabilitation is to return the person to the exact same job they had before, so employment fits nicely into burn rehabilitation but...

- What about the 65 year old who is retired?
- What about the 5 year old who has school re-entry issues but no employment issues?
- What about the homemaker (male or female)?
- What about the disabled person whose disability is so severe that he/she cannot work?

It might be argued that by focusing on employment, NIDRR is excluding many of the disabled from consideration.

But of course, perhaps current levels of funding will not permit addressing all problems, all needs; perhaps focus is required.

CONTRIBUTOR: Loren Engrav
University of Washington
engrav@u.washington.edu

DCN: 296

RECEIVED: 2/6/2009

COMMENT: I believe the NIDRR 2010-2014 Long-Range Plan does not serve the disabled community well. Instead of fostering research in the domains that have been the most effective, the 2010-14 draft plan is proposing to change its focus and provide funds for additional research to improve access to appropriate employment, retention of employment, and career advancement for individuals with disabilities. Although increasing employment for individuals with disabilities is a laudable goal, its priority should not be elevated vis-à-vis the health and function research domain.

The draft long-range plan contradicts government policy to link results to outcome measures. By NIDRR's own 2006 APAER review, the health and function portfolio determined that NIDRR has a long-standing, productive portfolio in health and function research the health and function portfolio has extremely productive. In contrast, the APAER expert review panel on employment (2006) determined that the level of scientific excellence was generally inadequate, lacking scientific rigor and hypothesis testing; the overall productivity of the portfolio was disappointing and limited; that consumers would likely find the portfolio to be disappointing. The panel also found that there is an adequate number of awards in the Employment portfolio. Given these facts, why is NIDRR increasing the focus on employment?

The development of new initiatives focusing on employment has forced NIDRR to eliminate priorities for productive RRTCs in area of neuromuscular disease, arthritis, TBI community reintegration and spinal cord injury. This will create severe hardships by these communities. For example, eliminating the priority for an RRTC in neuromuscular diseases has abolished the only federal support for medical rehabilitation of the 1 million people in the United States with a neuromuscular disease. The changes in policy put forth the proposed long-range plan will result in a substantial loss of productive health and function research just when the efforts of the investment made by NIDRR are coming to fruition. The changes proposed in NIDRR's long range plan are significantly different from NIDRR's mission, its long-standing policy, and its current 2005-2009 long-range plan.

CONTRIBUTOR: R. Ted Abresch
Department of Physical Medicine and Rehabilitation , UC Davis
tabresch@ucdavis.edu
(530) 752-9085

DCN: 297

RECEIVED: 2/6/2009

COMMENT: As a long-time Principal Investigator on a number of NIDRR funded grants, and currently Co-Director of a Model Spinal Cord Injury Care System grant, I must protest the proposed Long Range Plan for NIDRR. This plan is entirely too narrow in focus. Employment is an important issue; I have no quarrel with that. I do take exception to the fact that it is virtually the only focus in this plan, and ignores a host of other equally important priorities including interventions to improve health, community participation and quality of life via behavioral, technological and other interventions. I urge that the current plan be withdrawn and revised, with the goal of developing a more balanced and broad research agenda more reflective of what is actually important to persons with disabilities and the research community that serves them.

CONTRIBUTOR: J. Scott Richards, Ph.D., ABPP
University of Alabama at Birmingham
richards@uab.edu

DCN: 298

RECEIVED: 2/10/2009

COMMENT: I'm writing to express my concerns regarding the proposed NIDRR Long-Range Plan for 2010-2014. This proposal is alarmingly flawed and fails to support the full breadth of NIDRR's mission. NIDRR's mission is stated to improve the lives of individuals with disabilities and their opportunities for full participation in society. This mission has always had 3 crucial goals that together are vital components for improving the lives of all persons with disability:

1. health and function,
2. employment, and
3. community participation.

As currently written, NIDRR's new Long-Range Plan will place all of its energy on improving employment outcomes, and will only support health, function and community participation research, as long as the end goal is employment (Section III, Strategic Focus). All four of NIDRR's objectives for Research and Development (goal 1) are completely concentrated on employment, with almost every strategy designed to specifically address employment. Simply emphasizing employment is not only a grave mistake, but is in fact discriminatory. Is it only important to improve health and function for individuals who have the potential to return to work? NIDRR is sending a message that in essence is saying: it is no longer important to improve the lives of persons with disability who cannot return to work because it is not economical. Furthermore, the statement that employment is the key to economic self-sufficiency is completely inaccurate. Would it not also be economical to improve someone's independence enough to reduce the number of hours of care they needed? The goals as they are now set will create a tremendous surge of applications solely focused on employment. Every application will compete with the other to be more employment-oriented. This is extremely problematic as basic health, function and independence will be completely ignored in order to get NIDRR grants. With waning efforts to improve their outcomes, persons with disability who are unlikely to return to work will suffer, and ultimately so will their hope for independence and quality of life.

Rather than being an economical fix, this scenario is doomed to increase healthcare related costs by ignoring the health-related needs of all individuals with disabilities, especially those who have more severe disabilities. Moreover, if there is no longer an incentive to do research that will increase the health and independence of those who have severe disabilities, the long-term outcome will more likely be higher unemployment rates, not lower ones. Decreased health, functioning, and independence of those not returning to work will force caregivers to quit their jobs so that they may tend to the person with the disability. NIDRR does have a unique role; one that no other funding agency shares. NIDRR focuses on the whole person, whose ability to function and whose quality of life are dependent on the complex interaction of personal, societal, and environmental factors. NIDRR supports rehabilitation that is more closely tied to longer-term outcomes such as independence, community participation and employment. There is an obvious disparity between NIDRR's mission and their new objectives. If this goes unchanged, rehabilitation research is sure to suffer and the consequences will be monumental. NIDRR must reconsider the objectives of their Long-Range plan for 2010-2014 so that they equally support all three facets of rehabilitation independently:

1. health and function,
2. employment, and
3. community participation.

Thank you for your time and consideration on this very important matter.

CONTRIBUTOR: Dawn Neumann, Ph.D.
Carolinas Rehabilitation
dawn.neumann@carolinashealthcare.org
(704) 355-4211

DCN: 299

RECEIVED: 2/11/2009

COMMENT: Below are my comments on the proposed NIDRR Long-Range Plan:

1. The input of the field was ignored.
2. There was no pressing need to issue a new Long Range Plan on January 15, 2009. There was no argument made as to why a new plan needed to be developed. In other words, what was wrong with the old plan that resulted in the development of a new plan. Therefore taking the timing of the release of the document in conjunction with the lack of justification for a new long range plan suggests that it was addressing a political agenda rather than it being a strategic planning document.
3. Page 2565 bottom of the left column: "Unlike other Federal research entities, that support....acute rehabilitation research...NIDRR supports...." This statement contradicts fact as NIDRR does support conduct acute rehabilitation research, e.g., model system. What other Federal entities support acute rehabilitation research?
4. Most of the accomplishments cited are in the health and function area. What have been the accomplishments in the employment area?
5. Is there sufficient research capacity in the employment domain to implement high quality research?
6. What has been learned form already completed NIDRR research in the area? It is my understanding that internal performance review of the NIDRR employment research portfolio was very poor. What is the justification for spending additional dollars in an area that has produced so few noteworthy accomplishments? In contrast the review of health and function portfolio fared well and has seen a decrease of resources invested in this area over the past several years. Please justify this unwise management of resources.
7. The TBI and Burn Model systems have been eliminated from the discussion of program mechanisms. Is this a sign that those programs will not be re-competed?
8. The strategies that are listed are not research questions. Indeed most of the strategies that are described cannot be answered because they are not reachable. Thus there is a danger in attempting to implement this plan that NIDRR will lower its standards for quality research in order to comply with the goals of a political document.
9. If the goal is to increase employment of individuals with disabilities why not begin by addressing some basic policy issues that are barriers to employment, e.g. loss of entitlements, creating tax incentives for businesses to hire individuals with disabilities, including reduced mental processing speed as a reasonable accommodation for individuals with brain injury.
10. The Long Range Plan should be the foundation for an increased investment in rehabilitation research and disability research rather than a shift in focus with already meager dollars.
11. The statement that "THE" current focus of NIDRR is employment is a misrepresentation of the intent of Rehabilitation Act.

There is no question that the employment of individuals with disability is an important issue that needs to be addressed. However this line of inquiry should not be undertaken at the expense of research that has made considerable contributions to the quality of life of individuals with a disability and facilitated their ability to return to work for those who make that choice.

The Long Range Plan as proposed is flawed and cannot be merely re-written. If there is a Congressional directive to publish a new Long Range Plan then NIDRR would be wise to start from scratch. If there is no pressing reason to re-write the plan then I would suggest re-issuing the plan that was published under Kate Seelman.

CONTRIBUTOR: Wayne A. Gordon, Ph.D., ABPP/Cn
 Mount Sinai School of Medicine
 Wayne.Gordon@mountsinai.org
 (212) 659-9372

DCN: 300

RECEIVED: 2/12/2009

COMMENT: As the Director of the National Center for Personal Assistance Services at the University of California San Francisco, I am writing to endorse the statements from NARRTC that the proposed NIDRR Long Range plan(2010-2014) should be withdrawn because it would focus NIDRR's efforts on one outcome only — employment . We sent earlier comments on the NIDRR long range plan that were ignored. We want to see the proposed long range plan withdrawn and the current existing long range plan extended because it supports a broader agenda for NIDRR established by Congress, to foster disability and rehabilitation research designed to enhance self-determination and participation in the home, community, and workplace.

CONTRIBUTOR: Charlene Harrington, Ph.D., R.N.
University of California San Francisco
charlene.harrington@ucsf.edu
(415) 476-4030

DCN: 301

RECEIVED: 2/19/2009

COMMENT: I am writing to provide comment on NIDRR's recently released Long Range Plan. I write as a disability researcher who for many years now has received funding from NIDRR and who is the Chairman of the IOM panel that released the recent IOM report, "The Future of Disability in America."

From my reading of NIDRR's Long Range Plan, it is clear that NIDRR proposes on making the improvement of employment outcomes the focus of its long-range plan for FYs 2010-2014. Throughout the Plan, its goals, objectives, and strategies focus almost exclusively on improving employment outcomes and economic security for individuals with disabilities. I believe this is a regretful mistake.

In my letter of input provided to NIDRR I noted that, "There is much fear in the disability research community that NIDRR will develop a myopic and narrow focus on employment research in its coming Long Range Plan with a de-emphasis in some of the other areas it has historically supported including some of those noted in my recommendations. If this is true, I think it would be a major mistake for NIDRR to take such a narrow view and could result in the demise of the Agency as an important Federal Agency in the area of disability research." The NIDRR Long Range Plan realizes the fears expressed by the disability and rehabilitation research community and, if remain unchanged, will result in the ultimate demise of NIDRR as a viable Federal Agency in the arena of rehabilitation and disability research.

Historically, NIDRR has stood alone among Federal Research Agencies for its focus on supporting research that addresses the broad activity and participation dimensions of disability and health. The breadth and scope of its research is one of NIDRR's strengths and one of the reasons it is so highly respected by those of us who work in the rehabilitation and disability research arena. The current Plan is an unfortunately departure from NIDRR's breadth and scope of interest and will lead it to a position of marginal importance as a Federal Research Agency. In my view, it is essential that NIDRR continue its breadth of research focus, and not focus almost exclusively on the area of employment to the detriment of important advances in health and function, nonemployment domains of participation and community living. These are the topical areas not well addressed by other Federal Research Agencies interested in disability and are critical for improving the lives of person's with disability. All three areas have been under funded in the past and have the potential to make important new advances to improve the lives of person's with disability.

I am also disappointed to see little attention in the Plan to improving the agency's peer review process. The recent IOM Committee on The Future of Disability in America, which I chaired, felt strongly that while NIDRR has made many important improvements in its peer-review process and ongoing oversight and management of NIDRR grants, important changes were still needed. For many years NIDRR had been criticized in the research community for its poor peer review process and it has been very damaging to NIDRR's reputation and the respect it receives from the disability research community. I am sorry to see that of the several recommendations made by the IOM Committee for further improvements in the review and grant monitoring process, none appear to have made it into the Plan. In particular:

1. Implementing a standardized review process across NIDRR's entire research portfolio;
2. Including explicit consideration of the past performance of those submitting proposals within the evaluation criteria for new applications;
3. The creation of a mechanism to allow revision and resubmission for investigator initiated proposals;
4. The assignment of proposal scores based on the quality of the entire proposal, similar to the approaches taken by NTH and NSF;
5. Limiting reviews by the lay consumer members of review panels to the nontechnical aspects proposal; and finally
6. Providing more educational feedback on the reviews, especially for young and first time investigators.

Each of these recommendations is an important element for improving NIDRR's processes that the Committee hoped would be incorporated into NIDRR's Long Range Plan.

Thank you for the opportunity to provide input into the process.

CONTRIBUTOR: Alan M. Jette, P.T., Ph.D.
Boston University School of Public Health
hdr@bu.edu
(617) 638-1994

DCN: 302

RECEIVED: 2/23/2009

COMMENT: A. Comments supporting narrative in draft Long-Range Plan

I wish to applaud NIDRR's efforts to articulate its unique mission under the Rehabilitation Act, and within the context of all Federal agencies. I also wish to support NIDRR's articulation of the dual deliverables under its mission: knowledge from research and devices from development.

Section I. Introduction / Statutory Mandate (FR2564) includes a clear statement of the dual mission of conducting research project and development projects: NIDRR implements its statutory mandate by supporting research and development projects to generate new knowledge and products ... It appears that NIDRR is accurately differentiating between the conceptual knowledge generated by grantee research activity, and the tangible devices generated by grantee development activity.

The following page (FR2565) goes on to state, NIDRR also supports a wide range of rehabilitation engineering development activities, many of which lead to the manufacture and commercialization of products to enhance function or enable individuals to live and work more independently. NIDRR is clearly referencing tangible devices and services made available to the public through market forces, rather than conceptual knowledge made available to the public through publications.

On the same page (FR2565) under NIDRR Accomplishments, the plan goes into further detail to elaborate upon examples of knowledge outputs from research and product outputs from development, with the latter including Developing assistive technology and design features to make everyday products accessible to individuals with disabilities, including products marketed by companies such as AOL, Microsoft, Hewlett-Packard (HP), Black & Decker and Whirlpool.

Including these examples in the plan raises hope among advocates that NIDRR is working to ensure that grantee device outputs from development activities are relevant and applicable to the intended beneficiaries, just as NIDRR is working to ensure that grantee knowledge outputs from research activities are rigorous and applicable to these same beneficiaries.

B. Comments requesting modification to narrative in draft Long-Range Plan

Despite the above statement, language related to device development is not well represented in other portions of the draft Long Range Plan, and I urge inclusion of similar language to ensure that NIDRR's dual mission is clear to all stakeholders. Here are four examples:

1. First column, top paragraph on FR2565, lists various stakeholders relevant to NIDRR's mandate, but omits manufacturers or industry from this list. Given the important role of device development, transfer and commercialization activities, which cannot occur without private sector partners, I suggest that either term be inserted along with the other stakeholders, rather than implied under the phrase and others.
 2. Under the heading of Goals ' Research and Development (FR2566), the plan lists a series of Objectives and Strategies that related to research knowledge and its application through practices and policies, but not one single Objective and Strategy that specifically addresses the rehabilitation engineering development activity which was stated as leading to the manufacture and commercialization of tangible products in the marketplace. This appears to be a major gap in the articulation of Research AND Development Goals.
 3. The Program Mechanisms section (FR2568) is curiously silent on rehabilitation engineering development under the description of the RERC's program, and similarly silent on the parallel field-initiated research and development programs within the Field Initiated Projects paragraph.
 4. The Monitoring and Evaluation section (FR2568) is vague on the distinction between the research and development activities, in contrast to the clarity shown in the preceding sections. For example, the section does not differentiate information and products, from information as products, within the description. Further, the only mention of development activity outputs or outcomes is patents when this section could readily include invention disclosures, industry standards, clinical protocols, prototypes, licenses, instruments, tools freeware, royalties, and devices or services. All are evidence of outputs or outcomes from
-

development activities proposed by grantees under multiple programs (RERC, FIP, SBIR), and readily monitored and evaluated by NIDRR through the presence of tangible artifacts or evidence of application by external stakeholders ' including all of those mentioned earlier in the document.

I close by encouraging NIDRR to retain the new language that gives voice to those deliverables that directly benefit the target audiences of people with disabilities, but also follow through by providing the same attention to detail for development activities and their tangible products, as the document gives to research activities and their conceptual products. Such clarification is important to convey to all the stakeholders involved with NIDRR as a Federal agency.

CONTRIBUTOR: Joseph P. Lane, MBPA
University at Buffalo (SUNY)
joelane@buffalo.edu
(716) 829-3266

DCN: 303

RECEIVED: 2/24/2009

COMMENT: I write to express my concerns regarding the NIDRR Long Rang Plan's proposal to focus solely on Employment. Employment is a very important element of independent living, quality of life and function but does not encompass all of the areas that presently need knowledge development to move forward the lives of individuals with disability in our nation. I fear that this narrow focus is very short-sighted. NIDRR has been the leader in disability research. The prior long range plan with several areas of focus has spurred creativity and specialization among researchers and clinicians that have allowed great strides in daily function, independence, community integration, employment, quality of life, health and function. NIDRR's prior research focus on the health and function of individuals with disability has allowed our nation to learn how to improve function, and eventually, employment. NIDRR has built capacity and knowledge that has resulted in tremendous improvements in the lives of individuals with disabilities.

The medical treatment of individuals with disability is desperately lacking the evidence needed. Over the past decade numerous evidence-based reviews have been conducted, with almost all coming to similar conclusions: Insufficient evidence for Standards and very few Guidelines.

It is short-sighted to not realize that the focus on Health and Function is also furthering the cause of improving employment for individuals with disability. Without first learning how to best help some one with brain injury best recover from minimally conscious state, how will we ever be able to help that individual become employed? Without learning how to control emotional outbursts, how is someone with brain injury going to maintain their job? Without learning about the risks of coronary artery disease among individuals with spinal cord injury, how will individuals with spinal cord injury work their potential years in the workforce? Without determining what causes fatigue among individuals with TBI and multiple sclerosis, how will does someone battling these conditions make through the demands of full-time employment.

Not everyone with disability will be able to be employed. Should the resources of NIDRR go towards such a narrow aspect of the lives of those who are disabled? Don't the resources of NIDRR also need to go towards the goal of improving their lives as well through discovering ways to improve health, function, and community participation? What about children with disability with whom employment is not a possibility, but laying the ground works to healthy living, function, education, social skills, and community living is critical?

NIDRR needs a more comprehensive long range plan that better takes into account the lives of all individuals with disability, not just those who are ready for employment. Don't individuals with disability also need resources to be allocated to learning how to improve the lives of those that may not be able to be employed? What about the need to improve marital relationships? Decrease headaches following brain injury? Promote wound healing among individuals with SCI. Preventing heart disease? Treating depression?

NIDRR was established by the 1978 amendments of the Rehabilitation Act of 1973, as amended. As specified in section 200 of the Act, NIDRR's role is to:

- a) Support research, demonstration projects, training, and related activities to maximize the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities of all ages;
- b) Provide for a comprehensive and coordinated approach to the support and conduct of research, demonstrations projects, training, and related activities;
- c) Promote the transfer of rehabilitation technology;
- d) Ensure widespread distribution of practical scientific and technological information; and e) Increase opportunities for researchers who are members of minority groups and researchers who are individuals with disabilities.

It seems that the proposal to narrowly focus NIDRR's resources and efforts on employment does not support this mandate. What about full inclusion and integration into society? What about independent living? What about family support? What about social self-sufficiency? What about a comprehensive approach to conducting research, demonstration projects, training, and related activities? What about the transfer of technologies that may promote health, function, independent living, or community integration, but not directly relate to employment?

I urge NIDRR to consider expanding the Long Range Plan to include Health and Function and Community Participation.

CONTRIBUTOR: Vishwa S. Raj, M.D.
Carolinas Healthcare
vishwa.raj@carolinashealthcare.org
Carolinas Rehabilitation

DCN: 304

RECEIVED: 2/24/2009

COMMENT: I write to express my concerns regarding the NIDRR Long Rang Plan's proposal to focus solely on Employment. Employment is a very important element of independent living, quality of life and function but does not encompass all of the areas that presently need knowledge development to move forward the lives of individuals with disability in our nation. I fear that this narrow focus is very short-sighted. NIDRR has been the leader in disability research. The prior long range plan with several areas of focus has spurred creativity and specialization among researchers and clinicians that have allowed great strides in daily function, independence, community integration, employment, quality of life, health and function. NIDRR's prior research focus on the health and function of individuals with disability has allowed our nation to learn how to improve function, and eventually, employment. NIDRR has built capacity and knowledge that has resulted in tremendous improvements in the lives of individuals with disabilities.

The medical treatment of individuals with disability is desperately lacking the evidence needed. Over the past decade numerous evidence-based reviews have been conducted, with almost all coming to similar conclusions: Insufficient evidence for Standards and very few Guidelines.

It is short-sighted to not realize that the focus on Health and Function is also furthering the cause of improving employment for individuals with disability. Without first learning how to best help some one with brain injury best recover from minimally conscious state, how will we ever be able to help that individual become employed? Without learning how to control emotional outbursts, how is someone with brain injury going to maintain their job? Without learning about the risks of coronary artery disease among individuals with spinal cord injury, how will individuals with spinal cord injury work their potential years in the workforce? Without determining what causes fatigue among individuals with TBI and multiple sclerosis, how will does someone battling these conditions make through the demands of full-time employment.

Not everyone with disability will be able to be employed. Should the resources of NIDRR go towards such a narrow aspect of the lives of those who are disabled? Don't the resources of NIDRR also need to go towards the goal of improving their lives as well through discovering ways to improve health, function, and community participation? What about children with disability with whom employment is not a possibility, but laying the ground works to healthy living, function, education, social skills, and community living is critical?

NIDRR needs a more comprehensive long range plan that better takes into account the lives of all individuals with disability, not just those who are ready for employment. Don't individuals with disability also need resources to be allocated to learning how to improve the lives of those that may not be able to be employed? What about the need to improve marital relationships? Decrease headaches following brain injury? Promote wound healing among individuals with SCI. Preventing heart disease? Treating depression?

NIDRR was established by the 1978 amendments of the Rehabilitation Act of 1973, as amended. As specified in section 200 of the Act, NIDRR's role is to:

- a) Support research, demonstration projects, training, and related activities to maximize the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities of all ages;
- b) Provide for a comprehensive and coordinated approach to the support and conduct of research, demonstrations projects, training, and related activities;
- c) Promote the transfer of rehabilitation technology;
- d) Ensure widespread distribution of practical scientific and technological information; and
- e) Increase opportunities for researchers who are members of minority groups and researchers who are individuals with disabilities.

It seems that the proposal to narrowly focus NIDRR's resources and efforts on employment does not support this mandate. What about full inclusion and integration into society? What about independent living? What about family support? What about social self-sufficiency? What about a comprehensive approach to conducting research, demonstration projects, training, and related activities? What about the transfer of technologies that may promote health, function, independent living, or community integration, but not directly relate to employment?

I urge NIDRR to consider expanding the Long Range Plan to include Health and Function and Community Participation.

CONTRIBUTOR: Margaret Craig
Carolinas Rehabilitation
peg.craig@carolinashealthcare.org

DCN: 305

RECEIVED: 2/24/2009

COMMENT: I write to express my concerns regarding the NIDRR Long Rang Plan's proposal to focus solely on Employment. Employment is a very important element of independent living, quality of life and function but does not encompass all of the areas that presently need knowledge development to move forward the lives of individuals with disability in our nation. I fear that this narrow focus is very short-sighted. NIDRR has been the leader in disability research. The prior long range plan with several areas of focus has spurred creativity and specialization among researchers and clinicians that have allowed great strides in daily function, independence, community integration, employment, quality of life, health and function. NIDRR's prior research focus on the health and function of individuals with disability has allowed our nation to learn how to improve function, and eventually, employment. NIDRR has built capacity and knowledge that has resulted in tremendous improvements in the lives of individuals with disabilities.

The medical treatment of individuals with disability is desperately lacking the evidence needed. Over the past decade numerous evidence-based reviews have been conducted, with almost all coming to similar conclusions: Insufficient evidence for Standards and very few Guidelines.

It is short-sighted to not realize that the focus on Health and Function is also furthering the cause of improving employment for individuals with disability. Without first learning how to best help some one with brain injury best recover from minimally conscious state, how will we ever be able to help that individual become employed? Without learning how to control emotional outbursts, how is someone with brain injury going to maintain their job? Without learning about the risks of coronary artery disease among individuals with spinal cord injury, how will individuals with spinal cord injury work their potential years in the workforce? Without determining what causes fatigue among individuals with TBI and multiple sclerosis, how will does someone battling these conditions make through the demands of full-time employment.

Not everyone with disability will be able to be employed. Should the resources of NIDRR go towards such a narrow aspect of the lives of those who are disabled? Don't the resources of NIDRR also need to go towards the goal of improving their lives as well through discovering ways to improve health, function, and community participation? What about children with disability with whom employment is not a possibility, but laying the ground works to healthy living, function, education, social skills, and community living is critical?

NIDRR needs a more comprehensive long range plan that better takes into account the lives of all individuals with disability, not just those who are ready for employment. Don't individuals with disability also need resources to be allocated to learning how to improve the lives of those that may not be able to be employed? What about the need to improve marital relationships? Decrease headaches following brain injury? Promote wound healing among individuals with SCI. Preventing heart disease? Treating depression?

NIDRR was established by the 1978 amendments of the Rehabilitation Act of 1973, as amended. As specified in section 200 of the Act, NIDRR's role is to:

- a) Support research, demonstration projects, training, and related activities to maximize the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities of all ages;
- b) Provide for a comprehensive and coordinated approach to the support and conduct of research, demonstrations projects, training, and related activities;
- c) Promote the transfer of rehabilitation technology;
- d) Ensure widespread distribution of practical scientific and technological information; and
- e) Increase opportunities for researchers who are members of minority groups and researchers who are individuals with disabilities.

It seems that the proposal to narrowly focus NIDRR's resources and efforts on employment does not support this mandate. What about full inclusion and integration into society? What about independent living? What about family support? What about social self-sufficiency? What about a comprehensive approach to conducting research, demonstration projects, training, and related activities? What about the transfer of technologies that may promote health, function, independent living, or community integration, but not directly relate to employment?

I urge NIDRR to consider expanding the Long Range Plan to include Health and Function and Community Participation.

CONTRIBUTOR: Peter M. Cassidy
Carolinas Rehabilitation
peter.cassidy@carolinashealthcare.org
(704) 512-3345

DCN: 306

RECEIVED: 2/24/2009

COMMENT: I write to express my concerns regarding the NIDRR Long Rang Plan's proposal to focus solely on Employment. Employment is a very important element of independent living, quality of life and function but does not encompass all of the areas that presently need knowledge development to move forward the lives of individuals with disability in our nation. I fear that this narrow focus is very short-sighted. NIDRR has been the leader in disability research. The prior long range plan with several areas of focus has spurred creativity and specialization among researchers and clinicians that have allowed great strides in daily function, independence, community integration, employment, quality of life, health and function. NIDRR's prior research focus on the health and function of individuals with disability has allowed our nation to learn how to improve function, and eventually, employment. NIDRR has built capacity and knowledge that has resulted in tremendous improvements in the lives of individuals with disabilities.

The medical treatment of individuals with disability is desperately lacking the evidence needed. Over the past decade numerous evidence-based reviews have been conducted, with almost all coming to similar conclusions: Insufficient evidence for Standards and very few Guidelines.

It is short-sighted to not realize that the focus on Health and Function is also furthering the cause of improving employment for individuals with disability. Without first learning how to best help some one with brain injury best recover from minimally conscious state, how will we ever be able to help that individual become employed? Without learning how to control emotional outbursts, how is someone with brain injury going to maintain their job? Without learning about the risks of coronary artery disease among individuals with spinal cord injury, how will individuals with spinal cord injury work their potential years in the workforce? Without determining what causes fatigue among individuals with TBI and multiple sclerosis, how will does someone battling these conditions make through the demands of full-time employment.

Not everyone with disability will be able to be employed. Should the resources of NIDRR go towards such a narrow aspect of the lives of those who are disabled? Don't the resources of NIDRR also need to go towards the goal of improving their lives as well through discovering ways to improve health, function, and community participation? What about children with disability with whom employment is not a possibility, but laying the ground works to healthy living, function, education, social skills, and community living is critical?

NIDRR needs a more comprehensive long range plan that better takes into account the lives of all individuals with disability, not just those who are ready for employment. Don't individuals with disability also need resources to be allocated to learning how to improve the lives of those that may not be able to be employed? What about the need to improve marital relationships? Decrease headaches following brain injury? Promote wound healing among individuals with SCI. Preventing heart disease? Treating depression?

NIDRR was established by the 1978 amendments of the Rehabilitation Act of 1973, as amended. As specified in section 200 of the Act, NIDRR's role is to:

- a) Support research, demonstration projects, training, and related activities to maximize the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities of all ages;
- b) Provide for a comprehensive and coordinated approach to the support and conduct of research, demonstrations projects, training, and related activities;
- c) Promote the transfer of rehabilitation technology;
- d) Ensure widespread distribution of practical scientific and technological information; and
- e) Increase opportunities for researchers who are members of minority groups and researchers who are individuals with disabilities.

It seems that the proposal to narrowly focus NIDRR's resources and efforts on employment does not support this mandate. What about full inclusion and integration into society? What about independent living? What about family support? What about social self-sufficiency? What about a comprehensive approach to conducting research, demonstration projects, training, and related activities? What about the transfer of technologies that may promote health, function, independent living, or community integration, but not directly relate to employment?

I urge NIDRR to consider expanding the Long Range Plan to include Health and Function and Community Participation.

CONTRIBUTOR: Jane Cox
Carolinas Rehabilitation
jane.cox@carolinashealthcare.org
(704) 355-4406

DCN: 307

RECEIVED: 2/24/2009

COMMENT: I write to express my concerns regarding the NIDRR Long Rang Plan's proposal to focus solely on Employment. Employment is a very important element of independent living, quality of life and function but does not encompass all of the areas that presently need knowledge development to move forward the lives of individuals with disability in our nation. I fear that this narrow focus is very short-sighted. NIDRR has been the leader in disability research. The prior long range plan with several areas of focus has spurred creativity and specialization among researchers and clinicians that have allowed great strides in daily function, independence, community integration, employment, quality of life, health and function. NIDRR's prior research focus on the health and function of individuals with disability has allowed our nation to learn how to improve function, and eventually, employment. NIDRR has built capacity and knowledge that has resulted in tremendous improvements in the lives of individuals with disabilities.

The medical treatment of individuals with disability is desperately lacking the evidence needed. Over the past decade numerous evidence-based reviews have been conducted, with almost all coming to similar conclusions: Insufficient evidence for Standards and very few Guidelines.

It is short-sighted to not realize that the focus on Health and Function is also furthering the cause of improving employment for individuals with disability. Without first learning how to best help some one with brain injury best recover from minimally conscious state, how will we ever be able to help that individual become employed? Without learning how to control emotional outbursts, how is someone with brain injury going to maintain their job? Without learning about the risks of coronary artery disease among individuals with spinal cord injury, how will individuals with spinal cord injury work their potential years in the workforce? Without determining what causes fatigue among individuals with TBI and multiple sclerosis, how will does someone battling these conditions make through the demands of full-time employment.

Not everyone with disability will be able to be employed. Should the resources of NIDRR go towards such a narrow aspect of the lives of those who are disabled? Don't the resources of NIDRR also need to go towards the goal of improving their lives as well through discovering ways to improve health, function, and community participation? What about children with disability with whom employment is not a possibility, but laying the ground works to healthy living, function, education, social skills, and community living is critical?

NIDRR needs a more comprehensive long range plan that better takes into account the lives of all individuals with disability, not just those who are ready for employment. Don't individuals with disability also need resources to be allocated to learning how to improve the lives of those that may not be able to be employed? What about the need to improve marital relationships? Decrease headaches following brain injury? Promote wound healing among individuals with SCI. Preventing heart disease? Treating depression?

NIDRR was established by the 1978 amendments of the Rehabilitation Act of 1973, as amended. As specified in section 200 of the Act, NIDRR's role is to:

- a) Support research, demonstration projects, training, and related activities to maximize the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities of all ages;
- b) Provide for a comprehensive and coordinated approach to the support and conduct of research, demonstrations projects, training, and related activities;
- c) Promote the transfer of rehabilitation technology;
- d) Ensure widespread distribution of practical scientific and technological information; and
- e) Increase opportunities for researchers who are members of minority groups and researchers who are individuals with disabilities.

It seems that the proposal to narrowly focus NIDRR's resources and efforts on employment does not support this mandate. What about full inclusion and integration into society? What about independent living? What about family support? What about social self-sufficiency? What about a comprehensive approach to conducting research, demonstration projects, training, and related activities? What about the transfer of technologies that may promote health, function, independent living, or community integration, but not directly relate to employment?

I urge NIDRR to consider expanding the Long Range Plan to include Health and Function and Community Participation.

CONTRIBUTOR: Herbert L. Bonkovsky, M.D.
Carolinas Rehabilitation
herbert.bonkovsky@carolinashealthcare.org
704 355 3959

DCN: 308

RECEIVED: 2/24/2009

COMMENT: I write to express my concerns regarding the NIDRR Long Rang Plan's proposal to focus solely on Employment. Employment is a very important element of independent living, quality of life and function but does not encompass all of the areas that presently need knowledge development to move forward the lives of individuals with disability in our nation. I fear that this narrow focus is very short-sighted. NIDRR has been the leader in disability research. The prior long range plan with several areas of focus has spurred creativity and specialization among researchers and clinicians that have allowed great strides in daily function, independence, community integration, employment, quality of life, health and function. NIDRR's prior research focus on the health and function of individuals with disability has allowed our nation to learn how to improve function, and eventually, employment. NIDRR has built capacity and knowledge that has resulted in tremendous improvements in the lives of individuals with disabilities.

The medical treatment of individuals with disability is desperately lacking the evidence needed. Over the past decade numerous evidence-based reviews have been conducted, with almost all coming to similar conclusions: Insufficient evidence for Standards and very few Guidelines.

It is short-sighted to not realize that the focus on Health and Function is also furthering the cause of improving employment for individuals with disability. Without first learning how to best help some one with brain injury best recover from minimally conscious state, how will we ever be able to help that individual become employed? Without learning how to control emotional outbursts, how is someone with brain injury going to maintain their job? Without learning about the risks of coronary artery disease among individuals with spinal cord injury, how will individuals with spinal cord injury work their potential years in the workforce? Without determining what causes fatigue among individuals with TBI and multiple sclerosis, how will does someone battling these conditions make through the demands of full-time employment.

Not everyone with disability will be able to be employed. Should the resources of NIDRR go towards such a narrow aspect of the lives of those who are disabled? Don't the resources of NIDRR also need to go towards the goal of improving their lives as well through discovering ways to improve health, function, and community participation? What about children with disability with whom employment is not a possibility, but laying the ground works to healthy living, function, education, social skills, and community living is critical?

NIDRR needs a more comprehensive long range plan that better takes into account the lives of all individuals with disability, not just those who are ready for employment. Don't individuals with disability also need resources to be allocated to learning how to improve the lives of those that may not be able to be employed? What about the need to improve marital relationships? Decrease headaches following brain injury? Promote wound healing among individuals with SCI. Preventing heart disease? Treating depression?

NIDRR was established by the 1978 amendments of the Rehabilitation Act of 1973, as amended. As specified in section 200 of the Act, NIDRR's role is to:

- a) Support research, demonstration projects, training, and related activities to maximize the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities of all ages;
- b) Provide for a comprehensive and coordinated approach to the support and conduct of research, demonstrations projects, training, and related activities;
- c) Promote the transfer of rehabilitation technology;
- d) Ensure widespread distribution of practical scientific and technological information; and
- e) Increase opportunities for researchers who are members of minority groups and researchers who are individuals with disabilities.

It seems that the proposal to narrowly focus NIDRR's resources and efforts on employment does not support this mandate. What about full inclusion and integration into society? What about independent living? What about family support? What about social self-sufficiency? What about a comprehensive approach to conducting research, demonstration projects, training, and related activities? What about the transfer of technologies that may promote health, function, independent living, or community integration, but not directly relate to employment?

I urge NIDRR to consider expanding the Long Range Plan to include Health and Function and Community Participation.

CONTRIBUTOR: Flora Hammond, M.D.
Carolinas Rehabilitation
flora.hammond@carolinashealthcare.org
(704) 355-9330

DCN: 309

RECEIVED: 2/24/2009

COMMENT: I write to express my concerns regarding the NIDRR Long Rang Plan's proposal to focus solely on Employment. Employment is a very important element of independent living, quality of life and function but does not encompass all of the areas that presently need knowledge development to move forward the lives of individuals with disability in our nation. I fear that this narrow focus is very short-sighted. NIDRR has been the leader in disability research. The prior long range plan with several areas of focus has spurred creativity and specialization among researchers and clinicians that have allowed great strides in daily function, independence, community integration, employment, quality of life, health and function. NIDRR's prior research focus on the health and function of individuals with disability has allowed our nation to learn how to improve function, and eventually, employment. NIDRR has built capacity and knowledge that has resulted in tremendous improvements in the lives of individuals with disabilities.

The medical treatment of individuals with disability is desperately lacking the evidence needed. Over the past decade numerous evidence-based reviews have been conducted, with almost all coming to similar conclusions: Insufficient evidence for Standards and very few Guidelines.

It is short-sighted to not realize that the focus on Health and Function is also furthering the cause of improving employment for individuals with disability. Without first learning how to best help some one with brain injury best recover from minimally conscious state, how will we ever be able to help that individual become employed? Without learning how to control emotional outbursts, how is someone with brain injury going to maintain their job? Without learning about the risks of coronary artery disease among individuals with spinal cord injury, how will individuals with spinal cord injury work their potential years in the workforce? Without determining what causes fatigue among individuals with TBI and multiple sclerosis, how will does someone battling these conditions make through the demands of full-time employment.

Not everyone with disability will be able to be employed. Should the resources of NIDRR go towards such a narrow aspect of the lives of those who are disabled? Don't the resources of NIDRR also need to go towards the goal of improving their lives as well through discovering ways to improve health, function, and community participation? What about children with disability with whom employment is not a possibility, but laying the ground works to healthy living, function, education, social skills, and community living is critical?

NIDRR needs a more comprehensive long range plan that better takes into account the lives of all individuals with disability, not just those who are ready for employment. Don't individuals with disability also need resources to be allocated to learning how to improve the lives of those that may not be able to be employed? What about the need to improve marital relationships? Decrease headaches following brain injury? Promote wound healing among individuals with SCI. Preventing heart disease? Treating depression?

NIDRR was established by the 1978 amendments of the Rehabilitation Act of 1973, as amended. As specified in section 200 of the Act, NIDRR's role is to:

- a) Support research, demonstration projects, training, and related activities to maximize the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities of all ages;
- b) Provide for a comprehensive and coordinated approach to the support and conduct of research, demonstrations projects, training, and related activities;
- c) Promote the transfer of rehabilitation technology;
- d) Ensure widespread distribution of practical scientific and technological information; and
- e) Increase opportunities for researchers who are members of minority groups and researchers who are individuals with disabilities.

It seems that the proposal to narrowly focus NIDRR's resources and efforts on employment does not support this mandate. What about full inclusion and integration into society? What about independent living? What about family support? What about social self-sufficiency? What about a comprehensive approach to conducting research, demonstration projects, training, and related activities? What about the transfer of technologies that may promote health, function, independent living, or community integration, but not directly relate to employment?

I urge NIDRR to consider expanding the Long Range Plan to include Health and Function and Community Participation.

CONTRIBUTOR: Asim Salih Otey, M.D.
Carolinas Rehabilitation
salih.otey@carolinashealthcare.org

DCN: 310

RECEIVED: 2/24/2009

COMMENT: I write to express my concerns regarding the NIDRR Long Rang Plan's proposal to focus solely on Employment. Employment is a very important element of independent living, quality of life and function but does not encompass all of the areas that presently need knowledge development to move forward the lives of individuals with disability in our nation. I fear that this narrow focus is very short-sighted. NIDRR has been the leader in disability research. The prior long range plan with several areas of focus has spurred creativity and specialization among researchers and clinicians that have allowed great strides in daily function, independence, community integration, employment, quality of life, health and function. NIDRR's prior research focus on the health and function of individuals with disability has allowed our nation to learn how to improve function, and eventually, employment. NIDRR has built capacity and knowledge that has resulted in tremendous improvements in the lives of individuals with disabilities.

The medical treatment of individuals with disability is desperately lacking the evidence needed. Over the past decade numerous evidence-based reviews have been conducted, with almost all coming to similar conclusions: Insufficient evidence for Standards and very few Guidelines.

It is short-sighted to not realize that the focus on Health and Function is also furthering the cause of improving employment for individuals with disability. Without first learning how to best help some one with brain injury best recover from minimally conscious state, how will we ever be able to help that individual become employed? Without learning how to control emotional outbursts, how is someone with brain injury going to maintain their job? Without learning about the risks of coronary artery disease among individuals with spinal cord injury, how will individuals with spinal cord injury work their potential years in the workforce? Without determining what causes fatigue among individuals with TBI and multiple sclerosis, how will does someone battling these conditions make through the demands of full-time employment.

Not everyone with disability will be able to be employed. Should the resources of NIDRR go towards such a narrow aspect of the lives of those who are disabled? Don't the resources of NIDRR also need to go towards the goal of improving their lives as well through discovering ways to improve health, function, and community participation? What about children with disability with whom employment is not a possibility, but laying the ground works to healthy living, function, education, social skills, and community living is critical?

NIDRR needs a more comprehensive long range plan that better takes into account the lives of all individuals with disability, not just those who are ready for employment. Don't individuals with disability also need resources to be allocated to learning how to improve the lives of those that may not be able to be employed? What about the need to improve marital relationships? Decrease headaches following brain injury? Promote wound healing among individuals with SCI. Preventing heart disease? Treating depression?

NIDRR was established by the 1978 amendments of the Rehabilitation Act of 1973, as amended. As specified in section 200 of the Act, NIDRR's role is to:

- a) Support research, demonstration projects, training, and related activities to maximize the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities of all ages;
- b) Provide for a comprehensive and coordinated approach to the support and conduct of research, demonstrations projects, training, and related activities;
- c) Promote the transfer of rehabilitation technology;
- d) Ensure widespread distribution of practical scientific and technological information; and
- e) Increase opportunities for researchers who are members of minority groups and researchers who are individuals with disabilities.

It seems that the proposal to narrowly focus NIDRR's resources and efforts on employment does not support this mandate. What about full inclusion and integration into society? What about independent living? What about family support? What about social self-sufficiency? What about a comprehensive approach to conducting research, demonstration projects, training, and related activities? What about the transfer of technologies that may promote health, function, independent living, or community integration, but not directly relate to employment?

I urge NIDRR to consider expanding the Long Range Plan to include Health and Function and Community Participation.

CONTRIBUTOR: Janet L. Edsell, MA CCC-SLP
Carolinas Rehabilitation
janet.edsell@carolinashealthcare.org
(704) 355-4430

DCN: 311

RECEIVED: 2/25/2009

COMMENT: I am writing to express my profound disappointment in the Notice of proposed longrange plan for NIDRR. The proposed plan fails to recognize NIDRR's unique role, established by Congress, to foster disability and rehabilitation research designed to enhance self-determination and participation in the home, community, and workplace. NIDRR has a long record of fulfilling this unique role by focusing on three broad domains of research—health and function, employment, and community participation. Contrary to congressional intent and longstanding policy and practice, the Notice of NIDRR's proposed long range plan substantially departs from the current and previous plans by focusing on one category of research ' employment ' rather than on all three areas of research.

Contrary to Congressional intent and longstanding policy and practice, the Notice of NIDRR's proposed long range plan materially departs from previous plans by focusing on one category of research, employment, rather than on all three areas of research—health and function, employment and community participation. The references to nonemployment related search, including health and function research, appears to be made almost reluctantly.

The proposed NIDRR Long Range plan for 2010-2014 must be withdrawn because it would focus NIDRR's efforts on one outcome only—employment. I am distressed that NIDRR staff requested input from stakeholders and consumers of service and ignored what they had to say. NIDRR has a unique role, established by Congress, to foster disability and rehabilitation research designed to enhance self-determination and participation in the home, community, and workplace. This mandate should be respected and continued.

In addition, President Obama's 4 point disability agenda [www.whitehouse.gov/agenda/disabilities/] supports comprehensive, multiple foci to improve the lives of individuals with disabilities. His plan outlines the need for efforts designed to improve educational opportunities; restore the ADA, promote health and mental health care; increase community living opportunities for individuals with disabilities, as well as increasing employment.

I urge NIDRR to extend its existing Long Range Plan which is in fact, aligned with such a multi faceted agenda and urge NIDRR to withdraw its proposed Plan.

CONTRIBUTOR: Allen W. Heinemann, Ph.D., ABPP (RP), FACRM
Rehabilitation Institute of Chicago
a-heinemann@northwestern.edu
(312) 238-2802

DCN: 312

RECEIVED: 2/25/2009

COMMENT: I am a physician and researcher who have devoted my professional life to help individuals with disabilities, most particularly spinal cord injury, achieve and maintain good health in order to perform activities of their choice in the community, which is at the heart of the NIDRR mission statement. I am writing to voice my strong opposition to NIDRR's proposed Long Range Plan (2010-2014) because it diverges so radically from NIDRR's mission to support research that addresses the multifaceted needs of people with disabilities. While I concur with the importance of conducting research related to enhanced employment opportunities for individuals with disabilities, I must draw NIDRR's attention to the fact that without adherence to its mission to support research that addresses the multifaceted needs of people with disabilities, employment opportunities become a moot point. I urge NIDRR to withdraw the proposed Long Range Plan and to work with its constituency to get back on track.

Thank you for this opportunity to respond.

CONTRIBUTOR: Amie B. Jackson, M.D.
University of Alabama at Birmingham
jacksona@uab.edu

DCN: 313

RECEIVED: 2/25/2009

COMMENT: I write to voice my concerns regarding the NIDRR Long Rang Plan's proposal to focus solely on Employment. While I agree that employment is a very important element of independent living and quality of life, it does not encompass all of the areas that presently need knowledge development to move forward the lives of individuals with disability in our nation. The prior long range plan with several areas of focus has spurred creativity and specialization among researchers and clinicians that have allowed great strides in daily function, independence, community integration, employment, quality of life, health and function. NIDRR's prior research focus on the health and function of individuals with disability has allowed our nation to learn how to improve function, and eventually, employment. NIDRR has built capacity and knowledge that has resulted in tremendous improvements in the lives of individuals with disabilities. My concern is that a proposal whose sole focus is on employment will limit the funding that is available for research in the areas of health and function.

The medical treatment of individuals with disability is desperately lacking the evidence needed. Over the past decade numerous evidence-based reviews have been conducted, with almost all coming to similar conclusions: Insufficient evidence for Standards and very few Guidelines. As a physical therapist, I am at times frustrated by the lack of evidence that is there to support the treatment techniques that I utilize. Many third-party payers are not covering patients to be in our Emerging Responsiveness Program due to a lack of research demonstrating significant positive outcomes.

It seems logical that improving Health and Function will in turn further the cause of improving employment for individuals with disability. Without first learning how to best help some one with brain injury best recover from minimally conscious state, how will we ever be able to help that individual become employed? Without training the individual how to get out of bed, walk, or manage the assistive devices, how will they physically be able to perform their job duties? Without learning how to control emotional outbursts, how is someone with brain injury going to maintain their job?

Not everyone with disability will be able to be employed. Should the resources of NIDRR go towards such a narrow aspect of the lives of those who are disabled? Don't the resources of NIDRR also need to go towards the goal of improving their lives as well through discovering ways to improve health, function, and community participation? What about children with disability with whom employment is not a possibility, but laying the ground works to healthy living, function, education, social skills, and community living is critical?

NIDRR needs a more comprehensive long range plan that better takes into account the lives of all individuals with disability, not just those who are ready for employment. Don't individuals with disability also need resources to be allocated to learning how to improve the lives of those that may not be able to be employed? What about the need to improve marital relationships? Decrease headaches following brain injury? Promote wound healing among individuals with SCI. Preventing heart disease? Treating depression?

NIDRR was established by the 1978 amendments of the Rehabilitation Act of 1973, as amended. As specified in section 200 of the Act, NIDRR's role is to:

- a) Support research, demonstration projects, training, and related activities to maximize the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities of all ages;
- b) Provide for a comprehensive and coordinated approach to the support and conduct of research, demonstrations projects, training, and related activities;
- c) Promote the transfer of rehabilitation technology;
- d) Ensure widespread distribution of practical scientific and technological information; and
- e) Increase opportunities for researchers who are members of minority groups and researchers who are individuals with disabilities.

It seems that the proposal to narrowly focus NIDRR's resources and efforts on employment does not support this mandate. What about full inclusion and integration into society? What about independent living? What about family support? What about social self-sufficiency? What about a comprehensive approach to conducting research, demonstration projects, training, and related activities? What about the transfer of technologies that may promote health, function, independent living, or community integration, but not directly relate to employment?

I urge NIDRR to consider expanding the Long Range Plan to include Health and Function and Community Participation.

CONTRIBUTOR: Marla Richardson, MSPT, CBIS
Carolinas Rehabilitation
marla.richardson@carolinashealthcare.org

DCN: 314

RECEIVED: 2/25/2009

COMMENT: I write to express my concerns regarding the NIDRR Long Rang Plan's proposal to focus solely on Employment. Employment is a very important element of independent living, quality of life and function but does not encompass all of the areas that presently need knowledge development to move forward the lives of individuals with disability in our nation. I fear that this narrow focus is very short-sighted. NIDRR has been the leader in disability research. The prior long range plan with several areas of focus has spurred creativity and specialization among researchers and clinicians that have allowed great strides in daily function, independence, community integration, employment, quality of life, health and function. NIDRR's prior research focus on the health and function of individuals with disability has allowed our nation to learn how to improve function, and eventually, employment. NIDRR has built capacity and knowledge that has resulted in tremendous improvements in the lives of individuals with disabilities.

The medical treatment of individuals with disability is desperately lacking the evidence needed. Over the past decade numerous evidence-based reviews have been conducted, with almost all coming to similar conclusions: Insufficient evidence for Standards and very few Guidelines.

It is short-sighted to not realize that the focus on Health and Function is also furthering the cause of improving employment for individuals with disability. Without first learning how to best help some one with brain injury best recover from minimally conscious state, how will we ever be able to help that individual become employed? Without learning how to control emotional outbursts, how is someone with brain injury going to maintain their job? Without learning about the risks of coronary artery disease among individuals with spinal cord injury, how will individuals with spinal cord injury work their potential years in the workforce? Without determining what causes fatigue among individuals with TBI and multiple sclerosis, how will does someone battling these conditions make through the demands of full-time employment.

Not everyone with disability will be able to be employed. Should the resources of NIDRR go towards such a narrow aspect of the lives of those who are disabled? Don't the resources of NIDRR also need to go towards the goal of improving their lives as well through discovering ways to improve health, function, and community participation? What about children with disability with whom employment is not a possibility, but laying the ground works to healthy living, function, education, social skills, and community living is critical?

NIDRR needs a more comprehensive long range plan that better takes into account the lives of all individuals with disability, not just those who are ready for employment. Don't individuals with disability also need resources to be allocated to learning how to improve the lives of those that may not be able to be employed? What about the need to improve marital relationships? Decrease headaches following brain injury? Promote wound healing among individuals with SCI. Preventing heart disease? Treating depression?

NIDRR was established by the 1978 amendments of the Rehabilitation Act of 1973, as amended. As specified in section 200 of the Act, NIDRR's role is to:

- a) Support research, demonstration projects, training, and related activities to maximize the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities of all ages;
- b) Provide for a comprehensive and coordinated approach to the support and conduct of research, demonstrations projects, training, and related activities;
- c) Promote the transfer of rehabilitation technology;
- d) Ensure widespread distribution of practical scientific and technological information; and
- e) Increase opportunities for researchers who are members of minority groups and researchers who are individuals with disabilities.

It seems that the proposal to narrowly focus NIDRR's resources and efforts on employment does not support this mandate. What about full inclusion and integration into society? What about independent living? What about family support? What about social self-sufficiency? What about a comprehensive approach to conducting research, demonstration projects, training, and related activities? What about the transfer of technologies that may promote health, function, independent living, or community integration, but not directly relate to employment?

I urge NIDRR to consider expanding the Long Range Plan to include Health and Function and Community Participation.

CONTRIBUTOR: Marilyn Lash
North Carolina Traumatic Brain Injury Advisory Council
mlyn@lapublishing.com

DCN: 315

RECEIVED: 2/25/2009

COMMENT: It is my understanding that there is the intention to modify the focus on NIDRR where "improving of employment outcomes [will be] the focus of its long range plan for FYs 2010-2014." [74 FR at page 2544]. I am very concerned that the priorities of NIDRR would become so narrow as to only address the issue of employment, and of course we know that "employment" is an outcome that is nested in a much larger set of constructs like participation in the community and health and function. As a clinician working with people with disability, as a researcher in brain injury rehabilitation, and as a previous NIDRR grant reviewer I would strong urge you to maintain the foci that were in the two previous long-range plans, where NIDRR has recognized that in order to carry out its mission, research and development activities must focus on three major life domains:

- Employment,
- Participation and community living; and
- Health and function (including medical rehabilitation interventions to improve function and health status research to improve overall health and wellness of people with disabilities.

In addition, NIDRR has recognized the need to focus on technology for access and function and disability demographics.

CONTRIBUTOR: Lance E. Trexler, Ph.D., HSPP
Rehabilitation Hospital of Indiana
lance.trexler@rhin.com
(317) 879-8940

DCN: 316

RECEIVED: 2/26/2009

COMMENT: Having worked in the field of brain injury service since 1989, including vocational rehabilitation, I have seen remarkable progress in professional understanding of an extremely complex disability. While much has been learned about brain injury, there is so much that still needs to be learned about effectively treating a brain injury acutely and in the long term. Medications, treatment plans and meaningful therapies are essential to increasing independence and possible employment following a brain injury. TBI Model Systems are a critical piece to the development of meaningful and quality brain injury care.

I write to express my concerns regarding the NIDRR Long Rang Plan's proposal to focus solely on Employment. Employment is a very important element of independent living, quality of life and function but does not encompass all of the areas that presently need knowledge development to move forward the lives of individuals with disability in our nation. I fear that this narrow focus is very short-sighted. NIDRR has been the leader in disability research. The prior long range plan with several areas of focus has spurred creativity and specialization among researchers and clinicians that have allowed great strides in daily function, independence, community integration, employment, quality of life, health and function. NIDRR's prior research focus on the health and function of individuals with disability has allowed our nation to learn how to improve function, and eventually, employment. NIDRR has built capacity and knowledge that has resulted in tremendous improvements in the lives of individuals with disabilities.

The medical treatment of individuals with disability is desperately lacking the evidence needed. Over the past decade numerous evidence-based reviews have been conducted, with almost all coming to similar conclusions: Insufficient evidence for Standards and very few Guidelines.

It is short-sighted to not realize that the focus on Health and Function is also furthering the cause of improving employment for individuals with disability. Without first learning how to best help some one with brain injury best recover from minimally conscious state, how will we ever be able to help that individual become employed? Without learning how to control emotional outbursts, how is someone with brain injury going to maintain their job? Without learning about the risks of coronary artery disease among individuals with spinal cord injury, how will individuals with spinal cord injury work their potential years in the workforce? Without determining what causes fatigue among individuals with TBI and multiple sclerosis, how will does someone battling these conditions make through the demands of full-time employment.

Not everyone with disability will be able to be employed. Should the resources of NIDRR go towards such a narrow aspect of the lives of those who are disabled? Don't the resources of NIDRR also need to go towards the goal of improving their lives as well through discovering ways to improve health, function, and community participation? What about children with disability with whom employment is not a possibility, but laying the ground works to healthy living, function, education, social skills, and community living is critical?

NIDRR needs a more comprehensive long range plan that better takes into account the lives of all individuals with disability, not just those who are ready for employment. Don't individuals with disability also need resources to be allocated to learning how to improve the lives of those that may not be able to be employed? What about the need to improve marital relationships? Decrease headaches following brain injury? Promote wound healing among individuals with SCI. Preventing heart disease? Treating depression?

NIDRR was established by the 1978 amendments of the Rehabilitation Act of 1973, as amended. As specified in section 200 of the Act, NIDRR's role is to:

- a) Support research, demonstration projects, training, and related activities to maximize the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities of all ages;
- b) Provide for a comprehensive and coordinated approach to the support and conduct of research, demonstrations projects, training, and related activities;
- c) Promote the transfer of rehabilitation technology;
- d) Ensure widespread distribution of practical scientific and technological information; and
- e) Increase opportunities for researchers who are members of minority groups and researchers who are individuals with disabilities.

It seems that the proposal to narrowly focus NIDRR's resources and efforts on employment does not support this mandate. What about full inclusion and integration into society? What about independent living? What

about family support? What about social self-sufficiency? What about a comprehensive approach to conducting research, demonstration projects, training, and related activities? What about the transfer of technologies that may promote health, function, independent living, or community integration, but not directly relate to employment?

I urge NIDRR to consider expanding the Long Range Plan to include Health and Function and Community Participation.

CONTRIBUTOR: Sheri W. Bartel, M.Ed., CBIS
Carolinas Rehabilitation
sheri.bartel@carolinashealthcare.org
(704) 355-9623

DCN: 318

RECEIVED: 2/27/2009

COMMENT: The Institute for the Advancement of Social Work Research (IASWR) is pleased to have the opportunity to provide input into the National Institute on Disability and Rehabilitation Research's (NIDRR's) Long Range Plan for fiscal years 2010 through 2014. Social workers are a major provider of clinical care coordination services to persons with disabilities and their families, in employment, training, rehabilitation, primary care, mental and behavioral health, higher education, social services and other health and human service settings. Through social work research the profession:

- Assesses the needs and resources of people in their environments
- Evaluates the effectiveness of psychosocial interventions in meeting people's needs
- Demonstrates relative costs and benefits of such interventions
- Advances professional education in light of changing contexts for practice
- Examines the impact of legislation and social policy on the clients and communities we serve

The following are specific recommendations based on the draft NIDRR Long Range Plan. We hope that you will take them into consideration in building a comprehensive interdisciplinary research program at NIDRR.

Strategic Focus, 1st paragraph.

Recommendation: In regard to well documented disparity in rates of employment for individuals with ' as compared to individuals without ' disabilities, NIDRR should invest research and development to directly study mental health issues (more specifically psychosocial issues i.e. the constellation of social and emotional issues) and needs which affect one's ability to fully function both in and out of an employment setting. In other words, mental health needs to be distinguished from research that studies physical health.

Goal 1, Research and Development, Objective 1.1

Recommendation: Add language to include psychosocial factors. Increase knowledge of the educational, training, PSYCHOSOCIAL and socioeconomic factors that serve as facilitators of or barriers to improved employment outcomes for individuals with disabilities by supporting research and development on:

Goal 1, Research and Development, Objective(s) 1.2, 1.2.1, 1.2.2, 1.2.3

Recommendation: Add language to include MENTAL HEALTH as a separate component of health when they are described in each of the four listed objectives.

Goal 2, Knowledge Translation, Objective 2.1.3

Recommendation: While this objective is not overly specific about the exploration of existing models, methods and strategies from other fields social work should be included as an independent field to explore as a way to increase knowledge derived from NIDRR-funded research and development.

Program Mechanisms, 1st paragraph

Recommendation: Alter language to say MENTAL HEALTH or PSYCHOSOCIAL rather than psychological and social knowledge.

CONTRIBUTOR: Joan Levy Zlotnik
 Institute for the Advancement for Social Work Research (IASWR)
 jzlotnik@naswdc.org
 (202) 336-8393

DCN: 319

RECEIVED: 3/2/2009

COMMENT: People with disabilities nationwide still do not have full access to local community recreation resources and communities do not have a plan to address this need. Demonstration projects are needed just for this purpose, to help facilitate and integrate people into the everyday life of their communities. The Dept of Educ can do a great service in providing assistance to communities to start programming. The Dept could work through school districts and community recreation departments. In Madison, WI, we would like to apply for a demonstration project that would offer specialized activities like power soccer, as well as integrated services, like a scholarship program promoting that people get involved in local fitness clubs and related programming. Collaboration amongst public and private agencies is needed to accomplish this.

CONTRIBUTOR: Chad Thom
Madison, WI Public Schools
cthom@madison.k12.wi.us
(608) 204-3020

DCN: 320

RECEIVED: 3/4/2009

COMMENT: I am medical director of a large rehabilitation system in North Carolina as well as Chairman of the Department of Physical Medicine and Rehabilitation at Carolinas Medical Center in Charlotte, North Carolina. I have been involved with the disability community for over 20 years. I have been caring for a large population of patients with both severe spinal cord injury and severe brain injury. I am writing to express my concerns regarding the NIDRR Long Rang Plan's proposal to focus solely on Employment. Employment is a very important element of independent living, quality of life and function but does not encompass all of the areas that presently need knowledge development to move forward the lives of individuals with disability in our nation. I fear that this narrow focus is very short-sighted. NIDRR has been the leader in disability research. The prior long range plan with several areas of focus has spurred creativity and specialization among researchers and clinicians that have allowed great strides in daily function, independence, community integration, employment, quality of life, health and function. NIDRR's prior research focus on the health and function of individuals with disability has allowed our nation to learn how to improve function, and eventually, employment. NIDRR has built capacity and knowledge that has resulted in tremendous improvements in the lives of individuals with disabilities.

The medical treatment of individuals with disability is desperately lacking the evidence needed. Over the past decade numerous evidence-based reviews have been conducted, with almost all coming to similar conclusions: Insufficient evidence for Standards and very few Guidelines.

It is short-sighted to not realize that the focus on Health and Function is also furthering the cause of improving employment for individuals with disability. Without first learning how to best help some one with brain injury best recover from minimally conscious state, how will we ever be able to help that individual become employed? Without learning how to control emotional outbursts, how is someone with brain injury going to maintain their job? Without learning about the risks of coronary artery disease among individuals with spinal cord injury, how will individuals with spinal cord injury work their potential years in the workforce? Without determining what causes fatigue among individuals with TBI and multiple sclerosis, how will does someone battling these conditions make through the demands of full-time employment.

Not everyone with disability will be able to be employed. Should the resources of NIDRR go towards such a narrow aspect of the lives of those who are disabled? Don't the resources of NIDRR also need to go towards the goal of improving their lives as well through discovering ways to improve health, function, and community participation? What about children with disability with whom employment is not a possibility, but laying the ground works to healthy living, function, education, social skills, and community living is critical?

NIDRR needs a more comprehensive long range plan that better takes into account the lives of all individuals with disability, not just those who are ready for employment. Don't individuals with disability also need resources to be allocated to learning how to improve the lives of those that may not be able to be employed? What about the need to improve marital relationships? Decrease headaches following brain injury? Promote wound healing among individuals with SCI. Preventing heart disease? Treating depression?

NIDRR was established by the 1978 amendments of the Rehabilitation Act of 1973, as amended. As specified in section 200 of the Act, NIDRR's role is to:

- a) Support research, demonstration projects, training, and related activities to maximize the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities of all ages;
- b) Provide for a comprehensive and coordinated approach to the support and conduct of research, demonstrations projects, training, and related activities;
- c) Promote the transfer of rehabilitation technology;
- d) Ensure widespread distribution of practical scientific and technological information; and
- e) Increase opportunities for researchers who are members of minority groups and researchers who are individuals with disabilities.

It seems that the proposal to narrowly focus NIDRR's resources and efforts on employment does not support this mandate. What about full inclusion and integration into society? What about independent living? What about family support? What about social self-sufficiency? What about a comprehensive approach to conducting research, demonstration projects, training, and related activities? What about the transfer of

technologies that may promote health, function, independent living, or community integration, but not directly relate to employment?

I urge NIDRR to consider expanding the Long Range Plan to include Health and Function and Community Participation.

CONTRIBUTOR: William L. Bockenek, M.D.
Carolinas Rehabilitation
william.bockenek@carolinashealthcare.org
(704) 355-9330

DCN: 321

RECEIVED: 3/4/2009

COMMENT: I am writing on behalf of the Brain Injury Association of North Carolina to express my concerns regarding the NIDRR Long Rang Plan's proposal to focus solely on Employment. Employment is a very important element of independent living, quality of life and function but does not encompass all of the areas that presently need knowledge development to improve the lives of individuals with disability in our nation. I fear that this narrow focus is very short-sighted. NIDRR has been the leader in disability research. The prior long range plan with several areas of focus has spurred creativity and specialization among researchers and clinicians that have allowed great strides in daily function, independence, community integration, employment, quality of life, health and function. NIDRR's prior research focus on the health and function of individuals with disability has allowed our nation to learn how to improve function, and eventually, employment. NIDRR has built capacity and knowledge that has resulted in tremendous improvements in the lives of individuals with disabilities.

The medical treatment of individuals with disability is desperately lacking the evidence needed. Over the past decade numerous evidence-based reviews have been conducted, with almost all coming to similar conclusions: Insufficient evidence for Standards and very few Guidelines.

It is short-sighted to not realize that the focus on Health and Function is also furthering the cause of improving employment for individuals with disability. Without first learning how to best help some one with brain injury best recover from minimally conscious state, how will we ever be able to help that individual become employed? Without learning how to control emotional outbursts, how is someone with brain injury going to maintain their job? Without learning about the risks of coronary artery disease among individuals with spinal cord injury, how will individuals with spinal cord injury work their potential years in the workforce? Without determining what causes fatigue among individuals with TBI and multiple sclerosis, how will does someone battling these conditions make through the demands of full-time employment.

Not everyone with disability will be able to be employed. Should the resources of NIDRR go towards such a narrow aspect of the lives of those who are disabled? Don't the resources of NIDRR also need to go towards the goal of improving their lives as well through discovering ways to improve health, function, and community participation? What about children with disability with whom employment is not a possibility, but laying the ground works to healthy living, function, education, social skills, and community living is critical?

NIDRR needs a more comprehensive long range plan that better takes into account the lives of all individuals with disability, not just those who are ready for employment. Don't individuals with disability also need resources to be allocated to learning how to improve the lives of those that may not be able to be employed? What about the need to improve marital relationships? Decrease headaches following brain injury? Promote wound healing among individuals with SCI. Preventing heart disease? Treating depression?

NIDRR was established by the 1978 amendments of the Rehabilitation Act of 1973, as amended. As specified in section 200 of the Act, NIDRR's role is to:

- a) Support research, demonstration projects, training, and related activities to maximize the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities of all ages;
- b) Provide for a comprehensive and coordinated approach to the support and conduct of research, demonstrations projects, training, and related activities;
- c) Promote the transfer of rehabilitation technology;
- d) Ensure widespread distribution of practical scientific and technological information; and
- e) Increase opportunities for researchers who are members of minority groups and researchers who are individuals with disabilities.

It seems that the proposal to narrowly focus NIDRR's resources and efforts on employment does not support this mandate. What about full inclusion and integration into society? What about independent living? What about family support? What about social self-sufficiency? What about a comprehensive approach to conducting research, demonstration projects, training, and related activities? What about the transfer of technologies that may promote health, function, independent living, or community integration, but not directly relate to employment?

I urge NIDRR to consider expanding the Long Range Plan to include Health and Function and Community Participation.

CONTRIBUTOR: Sandra Farmer
Brain Injury Association of North Carolina
sfarmer.bianc@gmail.com

DCN: 322

RECEIVED: 3/4/2009

COMMENT: As the State Director for Vocational Rehabilitation in Massachusetts for over 30 years and as a person with a disability, I have long believed that NIDRR should have an R & T Center devoted to the economic status of people with disabilities and the cost benefit of programs defined in the Rehabilitation Act and their role of assisting people with disabilities to join the working world and/or stay working. A number of States, including Massachusetts, have done cost benefit studies (including Washington State, New Mexico, Florida, and Missouri). These studies have made a contribution to this goal, but we need a national approach, built on what has already been done, to build a national model and an agreement that it is true and accurate.

An R & T Center of this sort would be organized like any other R & T Center and would do the basic research, training, and dissemination of information to people who work in the public VR program nationwide and policy makers within the State and Federal Governments.

While being Director of VR in Massachusetts I funded two studies through the Commonwealth Corporation; one relative to cost benefit of VR in Massachusetts and another on the economic status of people with disabilities in Massachusetts. These two studies represent the best available information on the subjects reviewed as far as I know. The Commonwealth Corporation can be reached at: Nancy Snyder, President, Schrafft's Center, 529 Main Street, Suite 110, Boston, MA 02129, telephone number 617-727-8158, www.commcorp.org. These two studies are available on Commonwealth Corporation website under the Research and Evaluation Brief category.

If you are interested in a further develop proposal on this need, please get back in touch with me on such a request.

CONTRIBUTOR: Elmer C. Bartels
ECB Consulting
ecbartels@comcast.net
(781) 275-6078

DCN: 323

RECEIVED: 3/4/2009

COMMENT: RESNA, the Rehabilitation Engineering and Assistive Technology Society of North America, is an organization comprised of people with a common interest in assistive technology. As an organization, we support consumers who use assistive technology, as well as professionals who are engaged in AT research and development, education, advocacy and the provision of assistive technology. RESNA has a longstanding association with NIDRR and a keen interest in its long range plan. We ask NIDRR to consider two areas for improving its proposed long range plan.

RESNA feels that increasing employment of people with disabilities is a worthy goal, but we feel that a narrow focus on employment at the expense of health and function and community participation is a mistake. Assistive technology can play an important role in other important aspects of the lives of people with disabilities such as improving health, increasing function, promoting independence and fostering community participation. NIDRR-funded research has played a crucial role in the advancement of assistive technologies for a wide range of populations and purposes. We urge NIDRR to reconsider its proposed emphasis on employment, in favor of continuing its tradition of supporting a broad base of impacts.

RESNA also feels that NIDRR's peer-review process could be improved by incorporating policies of other funding agencies. Like the NIH, NIDRR should publish the rosters of each review panel; institute consistent submission deadlines for each funding program; provide a formal process for revising and resubmitting proposals; and release review scores for proposals in advance of funding decisions. Like the NSF, NIDRR should require explicit documentation of past performance with NIDRR funding in proposals, and incorporate this information into the review criteria.

Thank you for the opportunity to provide this input.

CONTRIBUTOR: Greg McGrew, MEMBE, President
Rich Simpson, Ph.D. Chair, Research Committee
Nell Bailey, Executive Director
Rehabilitation Engineering and Assistive Technology Society of North America (RESNA)
nbailey@resna.org
(703) 524-6686 ext. 305

DCN: 324

RECEIVED: 3/4/2009

COMMENT: I write to express my concerns regarding the NIDRR Long Rang Plan's proposal to focus solely on Employment. Employment is a very important element of independent living, quality of life and function but does not encompass all of the areas that presently need knowledge development to move forward the lives of individuals with disability in our nation. I fear that this narrow focus is very short-sighted. NIDRR has been the leader in disability research. The prior long range plan with several areas of focus has spurred creativity and specialization among researchers and clinicians that have allowed great strides in daily function, independence, community integration, employment, quality of life, health and function. NIDRR's prior research focus on the health and function of individuals with disability has allowed our nation to learn how to improve function, and eventually, employment. NIDRR has built capacity and knowledge that has resulted in tremendous improvements in the lives of individuals with disabilities.

The medical treatment of individuals with disability is desperately lacking the evidence needed. Over the past decade numerous evidence-based reviews have been conducted, with almost all coming to similar conclusions: Insufficient evidence for Standards and very few Guidelines.

It is short-sighted to not realize that the focus on Health and Function is also furthering the cause of improving employment for individuals with disability. Without first learning how to best help some one with brain injury best recover from minimally conscious state, how will we ever be able to help that individual become employed? Without learning how to control emotional outbursts, how is someone with brain injury going to maintain their job? Without learning about the risks of coronary artery disease among individuals with spinal cord injury, how will individuals with spinal cord injury work their potential years in the workforce? Without determining what causes fatigue among individuals with TBI and multiple sclerosis, how will does someone battling these conditions make through the demands of full-time employment.

Not everyone with disability will be able to be employed. Should the resources of NIDRR go towards such a narrow aspect of the lives of those who are disabled? Don't the resources of NIDRR also need to go towards the goal of improving their lives as well through discovering ways to improve health, function, and community participation? What about children with disability with whom employment is not a possibility, but laying the ground works to healthy living, function, education, social skills, and community living is critical?

NIDRR needs a more comprehensive long range plan that better takes into account the lives of all individuals with disability, not just those who are ready for employment. Don't individuals with disability also need resources to be allocated to learning how to improve the lives of those that may not be able to be employed? What about the need to improve marital relationships? Decrease headaches following brain injury? Promote wound healing among individuals with SCI. Preventing heart disease? Treating depression?

NIDRR was established by the 1978 amendments of the Rehabilitation Act of 1973, as amended. As specified in section 200 of the Act, NIDRR's role is to:

- a) Support research, demonstration projects, training, and related activities to maximize the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities of all ages;
- b) Provide for a comprehensive and coordinated approach to the support and conduct of research, demonstrations projects, training, and related activities;
- c) Promote the transfer of rehabilitation technology;
- d) Ensure widespread distribution of practical scientific and technological information; and
- e) Increase opportunities for researchers who are members of minority groups and researchers who are individuals with disabilities.

It seems that the proposal to narrowly focus NIDRR's resources and efforts on employment does not support this mandate. What about full inclusion and integration into society? What about independent living? What about family support? What about social self-sufficiency? What about a comprehensive approach to conducting research, demonstration projects, training, and related activities? What about the transfer of technologies that may promote health, function, independent living, or community integration, but not directly relate to employment?

I urge NIDRR to consider expanding the Long Range Plan to include Health and Function and Community Participation.

CONTRIBUTOR: Suzanne Snyder, PT, CPUM
Carolinas Rehabilitation
suzanne.snyder@carolinashealthcare.org
(704) 355-4493

DCN: 325

RECEIVED: 3/6/2009

COMMENT: I write to express my concerns regarding the NIDRR Long Rang Plan's proposal to focus solely on Employment. Employment is a very important element of independent living, quality of life and function but does not encompass all of the areas that presently need knowledge development to move forward the lives of individuals with disability in our nation. I fear that this narrow focus is very short-sighted. NIDRR has been the leader in disability research. The prior long range plan with several areas of focus has spurred creativity and specialization among researchers and clinicians that have allowed great strides in daily function, independence, community integration, employment, quality of life, health and function. NIDRR's prior research focus on the health and function of individuals with disability has allowed our nation to learn how to improve function, and eventually, employment. NIDRR has built capacity and knowledge that has resulted in tremendous improvements in the lives of individuals with disabilities.

The medical treatment of individuals with disability is desperately lacking the evidence needed. Over the past decade numerous evidence-based reviews have been conducted, with almost all coming to similar conclusions: Insufficient evidence for Standards and very few Guidelines.

It is short-sighted to not realize that the focus on Health and Function is also furthering the cause of improving employment for individuals with disability. Without first learning how to best help some one with brain injury best recover from minimally conscious state, how will we ever be able to help that individual become employed? Without learning how to control emotional outbursts, how is someone with brain injury going to maintain their job? Without learning about the risks of coronary artery disease among individuals with spinal cord injury, how will individuals with spinal cord injury work their potential years in the workforce? Without determining what causes fatigue among individuals with TBI and multiple sclerosis, how will does someone battling these conditions make through the demands of full-time employment.

Not everyone with disability will be able to be employed. Should the resources of NIDRR go towards such a narrow aspect of the lives of those who are disabled? Don't the resources of NIDRR also need to go towards the goal of improving their lives as well through discovering ways to improve health, function, and community participation? What about children with disability with whom employment is not a possibility, but laying the ground works to healthy living, function, education, social skills, and community living is critical?

NIDRR needs a more comprehensive long range plan that better takes into account the lives of all individuals with disability, not just those who are ready for employment. Don't individuals with disability also need resources to be allocated to learning how to improve the lives of those that may not be able to be employed? What about the need to improve marital relationships? Decrease headaches following brain injury? Promote wound healing among individuals with SCI. Preventing heart disease? Treating depression?

NIDRR was established by the 1978 amendments of the Rehabilitation Act of 1973, as amended. As specified in section 200 of the Act, NIDRR's role is to:

- a) Support research, demonstration projects, training, and related activities to maximize the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities of all ages;
- b) Provide for a comprehensive and coordinated approach to the support and conduct of research, demonstrations projects, training, and related activities;
- c) Promote the transfer of rehabilitation technology;
- d) Ensure widespread distribution of practical scientific and technological information; and
- e) Increase opportunities for researchers who are members of minority groups and researchers who are individuals with disabilities.

It seems that the proposal to narrowly focus NIDRR's resources and efforts on employment does not support this mandate. What about full inclusion and integration into society? What about independent living? What about family support? What about social self-sufficiency? What about a comprehensive approach to conducting research, demonstration projects, training, and related activities? What about the transfer of technologies that may promote health, function, independent living, or community integration, but not directly relate to employment?

I urge NIDRR to consider expanding the Long Range Plan to include Health and Function and Community Participation and to include research as an integral part of The Plan.

CONTRIBUTOR: James T. McDeavitt, M.D.
Carolinas Medical Center
james.mcdeavitt@carolinashealthcare.org
(704) 355-3146

DCN: 326

RECEIVED: 3/6/2009

COMMENT: I write to express my concerns regarding the NIDRR Long Rang Plan's proposal to focus solely on Employment. Employment is a very important element of independent living, quality of life and function but does not encompass all of the areas that presently need knowledge development to move forward the lives of individuals with disability in our nation. I fear that this narrow focus is very short-sighted. NIDRR has been the leader in disability research. The prior long range plan with several areas of focus has spurred creativity and specialization among researchers and clinicians that have allowed great strides in daily function, independence, community integration, employment, quality of life, health and function. NIDRR's prior research focus on the health and function of individuals with disability has allowed our nation to learn how to improve function, and eventually, employment. NIDRR has built capacity and knowledge that has resulted in tremendous improvements in the lives of individuals with disabilities.

The medical treatment of individuals with disability is desperately lacking the evidence needed. Over the past decade numerous evidence-based reviews have been conducted, with almost all coming to similar conclusions: Insufficient evidence for Standards and very few Guidelines.

It is short-sighted to not realize that the focus on Health and Function is also furthering the cause of improving employment for individuals with disability. Without first learning how to best help some one with brain injury best recover from minimally conscious state, how will we ever be able to help that individual become employed? Without learning how to control emotional outbursts, how is someone with brain injury going to maintain their job? Without learning about the risks of coronary artery disease among individuals with spinal cord injury, how will individuals with spinal cord injury work their potential years in the workforce? Without determining what causes fatigue among individuals with TBI and multiple sclerosis, how will does someone battling these conditions make through the demands of full-time employment.

Not everyone with disability will be able to be employed. Should the resources of NIDRR go towards such a narrow aspect of the lives of those who are disabled? Don't the resources of NIDRR also need to go towards the goal of improving their lives as well through discovering ways to improve health, function, and community participation? What about children with disability with whom employment is not a possibility, but laying the ground works to healthy living, function, education, social skills, and community living is critical?

NIDRR needs a more comprehensive long range plan that better takes into account the lives of all individuals with disability, not just those who are ready for employment. Don't individuals with disability also need resources to be allocated to learning how to improve the lives of those that may not be able to be employed? What about the need to improve marital relationships? Decrease headaches following brain injury? Promote wound healing among individuals with SCI. Preventing heart disease? Treating depression?

NIDRR was established by the 1978 amendments of the Rehabilitation Act of 1973, as amended. As specified in section 200 of the Act, NIDRR's role is to:

- a) Support research, demonstration projects, training, and related activities to maximize the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities of all ages;
- b) Provide for a comprehensive and coordinated approach to the support and conduct of research, demonstrations projects, training, and related activities;
- c) Promote the transfer of rehabilitation technology;
- d) Ensure widespread distribution of practical scientific and technological information; and
- e) Increase opportunities for researchers who are members of minority groups and researchers who are individuals with disabilities.

It seems that the proposal to narrowly focus NIDRR's resources and efforts on employment does not support this mandate. What about full inclusion and integration into society? What about independent living? What about family support? What about social self-sufficiency? What about a comprehensive approach to conducting research, demonstration projects, training, and related activities? What about the transfer of technologies that may promote health, function, independent living, or community integration, but not directly relate to employment?

I urge NIDRR to consider expanding the Long Range Plan to include Health and Function and Community Participation.

CONTRIBUTOR: Tiffini Molesky
Carolinas Medical Center
tiffini.molesky@carolinashealthcare.org

DCN: 327

RECEIVED: 3/9/2009

COMMENT: The Burton Blatt Institute (BBI) at Syracuse University wishes to comment on the NIDRR Long Range Plan (LRP). Upon review of the plan, we have several concerns with the LRP, falling into three categories: 'omission of ADA technical assistance activities, focus of the plan solely on employment, and alignment with the new administration's disability agenda.

Omission of ADA Technical Assistance Activities through Direct Services to Consumers

BBI is concerned that the LRP does not acknowledge NIDRR's responsibilities to provide information, training and technical assistance on the Americans with Disabilities Act (ADA). It does not provide direction regarding: 1) how its technical assistance project (DBTAC-ADA Centers) will be managed; 2) how necessary resources will be allocated, and 3) how activities will be coordinated with other federal efforts on ADA implementation. It is BBI's understanding that NIDRR is specifically charged with carrying out these activities as follows:

According to 29 U.S.C. 762, NIDRR and the Secretary are charged with: (11) coordinating activities with the Attorney General regarding the provision of information, training, or technical assistance regarding the Americans with Disabilities Act of 1990 (42 U.S.C.12101 et seq.) to ensure consistency with the plan for technical assistance required under section 506 of such Act (42 U.S.C. 12206)

NIDRR's omission in its LRP of technical assistance on the ADA is a major concern for BBI, as we believe technical assistance is, and will continue to be, critical to implementation of the ADA. The ADA is complex legislation that is not easily understood by the general population. The ADA establishes the necessary minimum standards for many types of environments, including work, state and local government, and public accommodations. It is a critical piece of civil rights legislation that continues to be recognized as a model in the rest of the world. The ADA was written by lawyers and legislators, but is intended to be implemented voluntarily. Without plain-English explanation and practical solutions, such voluntary compliance will be difficult to achieve. Congress recognized this in the absolute requirement of Title V of the ADA that executive branch agencies develop plans to assist entities covered by the law in understanding their ADA rights and responsibilities through the provision of information and technical assistance about compliance strategies. 42 U.S.C. 12206.

Many ADA terms and requirements are not easily understood by the general population, including the meanings of disability, reasonable accommodation, undue hardship, reasonable modification of policies, practices and procedures, readily achievable barrier removal, effective communication, direct threat, and undue burden. In addition, the ADA Amendments Act provided significant changes to the definition of disability, which will add to the complexity of voluntary compliance.

Individuals with disabilities, employers, government agencies, and businesses also need access to practical expertise and experience in order to properly implement ADA requirements, such as ensuring accessible information technology and effectively removing physical barriers. Direct service delivery is vital to ensure this level of expertise is available to the public. The questions our DBTAC-Southeast ADA Center receives on the ADA technical assistance phone line (1-800-949-4232) are more complex and novel than at any time in the past 18 years requiring more research and discussion on the part of technical assistance staff. In addition, keeping the public informed of court decisions relative to the ADA has grown in complexity and importance. With the passage of ADA Amendments Act (January 09) and the development of new ADA regulations, explanations of the ADA to the general public will be even more critical and intricate in the near future.

BBI also believes it is critical that any technical assistance delivery system be comprehensive, covering all areas affected by the ADA, including education, housing, transportation, employment, community access, civic participation, access to healthcare, recreation, and information technology. The ADA covers all these areas with a consistent civil rights approach. The technical assistance across these areas should similarly be comprehensive and consistent.

Narrow Focus Solely on Employment

The Long Range Plan (LRP) focuses on employment, omitting the many other areas that affect disability. NIDRR's mission to support research and related activities to generate new knowledge and promote its effective use to improve the lives of people with disabilities and their opportunities for full participation in society is not reflected in the current LRP. By focusing the LRP exclusively on employment, NIDRR

erroneously narrows its scope and neglects the concept of full participation. Employment cannot be addressed in a vacuum ' employment opportunities for people with disabilities are affected by other areas, such as economic status, transportation, education, housing, and health care. In addition, employment is not the sole focus of independent living. One goal of the ADA is to achieve full inclusion for people with disabilities in society, including social participation (e.g., recreation, volunteerism), civic participation (e.g., voting and accessing government services), and fiscal participation (e.g., economic self-sufficiency, buying and selling goods and services).

By focusing only on employment issues, the LRP ignores areas relevant to the needs of children and seniors with disabilities, whose needs often differ from working-age adults. Improving health and function and community participation for both of these groups should be critical goals contained in NIDRR's long-range plan.

Not only does the narrow scope of the LRP ignore NIDRR's broader mission, but narrowly focusing solely on employment to the exclusion of other factors that affect employment will limit the effectiveness of NIDRR's employment-related activities. One's education, socioeconomic status, health, transportation and access to government services and public accommodations interplay with one's ability to work. For people with disabilities, this interplay is even more significant. Therefore, we believe NIDRR must give each arena of life weight in the LRP. We strongly recommend NIDRR to expand its emphasis to reflect that employment depends on the rest of life: education, access to public accommodations and government services, health care, transportation and community living.

Misalignment with Administration's Disability Agenda

BBI has strong concerns regarding the inconsistency between the LRP and the new administration's disability agenda [<http://www.whitehouse.gov/agenda/disabilities/>]. President Obama's 4-point disability agenda outlines a comprehensive approach to improve the lives of individuals with disabilities. The plan outlines the need for efforts designed to:

1. improve educational opportunities;
2. restore the ADA;
3. increase employment; and
4. increase community living opportunities for individuals with disabilities.

NIDRR's current Long Range Plan focuses on only one of these four goals - employment, and does not acknowledge the importance of compliance with existing laws to improve overall quality of life for people with disabilities. The new administration's plan specifically states that full implementation of IDEA, the ADA, and the Community Choice Act, as well as better access to health care is the foundation of its disability policy. The LRP fails to address any part of the administration's disability agenda. BBI believes a unified commitment from all agencies to carry out an overall disability agenda as directed by the current administration is the most effective way to improve the quality of life for people with disabilities.

In conclusion, BBI recommends that NIDRR to withdraw the LRP and make revisions to more accurately reflect Congress' intention when it established the agency. This re-drafted LRP should more closely reflect a disability and rehabilitation research agenda designed to enhance self-determination and participation in the home, community, and workplace through research, technical assistance, training, and dissemination activities. The LRP must reaffirm NIDRR's commitment to provide technical assistance in the form of information and training activities provided directly to consumers. We also recommend that the revised LRP better align its goals, objectives, and philosophy with those of the new administration.

CONTRIBUTOR: Eve L. Hill
Burton Blatt Institute
ehill@law.syr.edu
(202) 296-2044

DCN: 328

RECEIVED: 3/10/2009

COMMENT: I have reviewed NIDRR's long range plan have submit the following comments on behalf of Boley Centers, Inc. Boley Center's is a non-profit psychosocial rehabilitation center located in St. Petersburg, Florida and primarily serving individuals with mental illnesses.

The ADA is a comprehensive and complex law and not easily understood by the general population including our organization's constituency. NIDRR's omission in its LRP of technical assistance on the ADA is a major concern for us and our work with the National DBTAC network. We believe technical assistance is, and will continue to be, critical to implementation of the Americans with Disabilities Act. Direct service by provided by key experts available through the DBTAC network is vital to keeping the public informed of its ADA rights, responsibilities, including court decisions. Now that the ADA Amendments Act of 2008 are law, combined with the impending major changes to the ADA regulations and design standards, technical assistance and training services offered through the DBTACs is more important than ever before.

NIDRR's LRP focuses only on employment. NIDRR's full mission is more broad, as posted on their website: to support research and related activities to generate new knowledge and promote its effective use to improve the lives of people with disabilities and their opportunities for full participation in society. Focusing exclusively on employment neglects the concept of full participation. For people with disabilities to achieve full participation in society, the full continuum of inclusion including community participation, transportation, housing education, mental health, physical health and function must be addressed.

Boley Centers, Inc. is concerned about the inconsistency between NIDRR's LRP and the new administration's disability agenda (<http://www.whitehouse.gov/agenda/disabilities/>). President Obama's 4-point disability agenda outlines a comprehensive approach to improve the lives of individuals with disabilities. The plan outlines the need for efforts designed to:

1. improve educational;
2. restore the ADA;
3. promote health and mental health care; and,
4. increase community living opportunities for individuals with disabilities including improved employment outcomes.

NIDRR's proposed LRP fails to address any part of the administration's disability agenda. We believe that a unified commitment from all agencies to carry out an overall disability agenda as directed by the current administration is the most effective way to improve the quality of life for people with disabilities.

Therefore, we recommend that NIDRR re-draft the draft Long-Range Plan for Fiscal Years 2010 '2014 and make revisions to more accurately reflect Congress' intention when it established the agency. The LRP must reaffirm NIDRR's obligation to provide technical assistance in the form of information and training activities provided directly to individuals. We also recommend that the revised LRP better align its goals, objectives, and philosophy with those of the new administration.

CONTRIBUTOR: Jack Humburg
Boley Centers, Inc
jackhumburg@boleycenters.org

DCN: 329

RECEIVED: 3/10/2009

COMMENT: Partnerships in Assistive Technology is a non-profit organization that manages a number of projects related to disability and technology issues. We are concerned that NIDRR's draft Long-Range Plan for Fiscal Years 2010-2014 does not include funding for the DBTAC program to continue providing much-needed direct core services to facilitate voluntary ADA compliance.

The ADA is a comprehensive and complex law and not easily understood by the general population including our organization's constituency. NIDRR's omission in its LRP of technical assistance on the ADA is a major concern for us and our work with the National DBTAC network. We believe technical assistance is, and will continue to be, critical to implementation of the Americans with Disabilities Act. Direct service by provided by key experts available through the DBTAC network is vital to keeping the public informed of its ADA rights, responsibilities, including court decisions. Now that the ADA Amendments Act of 2008 are law, combined with the impending major changes to the ADA regulations and design standards, technical assistance and training services offered through the DBTACs is more important than ever before.

NIDRR's LRP focuses only on employment. NIDRR's full mission is more broad, as posted on their website: to support research and related activities to generate new knowledge and promote its effective use to improve the lives of people with disabilities and their opportunities for full participation in society. Focusing exclusively on employment neglects the concept of full participation. For people with disabilities to achieve full participation in society, the full continuum of inclusion including community participation, transportation, housing education, and health and function must be addressed.

Partnerships in Assistive Technology is concerned about the inconsistency between NIDRR's LRP and the new administration's disability agenda (<http://www.whitehouse.gov/agenda/disabilities/>). President Obama's 4-point disability agenda outlines a comprehensive approach to improve the lives of individuals with disabilities. The plan outlines the need for efforts designed to:

1. improve educational;
2. restore the ADA;
3. promote health and mental health care; and,
4. increase community living opportunities for individuals with disabilities including improved employment outcomes.

NIDRR's proposed LRP fails to address any part of the administration's disability agenda. We believe that a unified commitment from all agencies to carry out an overall disability agenda as directed by the current administration is the most effective way to improve the quality of life for people with disabilities.

Therefore, we recommend that NIDRR re-draft the draft Long-Range Plan for Fiscal Years 2010 '2014 and make revisions to more accurately reflect Congress' intention when it established the agency. The LRP must reaffirm NIDRR's obligation to provide technical assistance in the form of information and training activities provided directly to individuals. We also recommend that the revised LRP better align its goals, objectives, and philosophy with those of the new administration.

CONTRIBUTOR: Sonya Van Horn, MS, ATP
Partnerships in Assistive Technology
assist@pat.org
(919) 872-2298

DCN: 330

RECEIVED: 3/10/2009

COMMENT: Thank you for the opportunity to comment on NIDRR's long range plan. I support NIDRR's focus on employment outcomes for individuals with disability. As a pediatric physical therapist and researcher, I advocate for continued support of pediatric research. Our understanding of the determinants of participation in home, school, and community life for children and the factors that promote self-determination are essential in order to prepare children and youth with the skills necessary to ensure a successful transition to adulthood and positive post-secondary outcomes such as employment.

CONTRIBUTOR: Lisa Chiarello, PT, Ph.D., PCS
Drexel University
lc38@drexel.edu

DCN: 331

RECEIVED: 3/10/2009

COMMENT: As the director of a center for independent living that also serves as the ADA Network for Mississippi, under contract with the Southeastern DBTAC, I am very concerned with NIDRR's Long Range Plan for FY 2010 - 2014. It appears that all technical assistance currently provided by the DBTAC networks has been removed. This aspect of our work is critical. The ADA is a complex law and not easily understood by the general public. We spend a vast majority of our time providing information, explaining points and conducting training to people with disabilities, the general public, state and local governments and private businesses. Now that the ADA Amendments Act of 2008 has passed, we expect a higher volume of technical assistance needs and calls from individuals and businesses needing information and training, a service that has been provided well through the DBTAC's and one that we have been trained extensively to conduct.

According to the mission statement posted on NIDRR's website, you "support research and related activities to generate new knowledge and promote its effective use to improve the lives of people with disabilities and their opportunities for full participation in society. The long range plan indicates that NIDRR will focus solely on employment issues, yet your mission statement is much broader than employment. As a center for independent living that transitions individuals from nursing facilities and back into the community, we know that "opportunities for full participation" means much more than just employment, it is also ensuring least restrictive environments, ensuring public accessibility including housing, transportation, medical offices and more.

President Obama's 4-point disability agenda outlines a comprehensive approach to improve the lives of individuals with disabilities. The plan outlines the need for efforts designed to:

1. improve education;
2. restore the ADA;
3. promote health and mental health care; and,
4. increase community living opportunities for individuals with disabilities including improved employment outcomes.

NIDRR's proposed LRP fails to address any part of the administration's disability agenda. We believe that a unified commitment from all agencies to carry out an overall disability agenda as directed by the current administration is the most effective way to improve the quality of life for people with disabilities.

Living Independence For Everyone (LIFE) of Mississippi is recommending that NIDRR revise their long range plan for FY 2010 - 2014 and accurately reflect Congress' intention for NIDRR to provide technical assistance, information and referral and training activities to individuals with disabilities and to better align its goals and objectives with those of the new administration.

Thank you for the opportunity to comment.

CONTRIBUTOR: Christy Dunaway
LIFE of Mississippi, Inc.
lifeofms@aol.com

DCN: 332

RECEIVED: 3/10/2009

COMMENT: I would like to provide comments to the Assistant Secretary for Special Education and Rehabilitative Services regarding the proposed long range plan (FYs 2010-2014) for the National Institute on Disability and Rehabilitation Research (NIDRR). Specifically I am concerned that the change in focus emphasizing employment and de-emphasizing Participation and Health and Function is not consistent with the needs of persons who want to be fully integrated, including competitively employed.

NIDRR has in the past and should continue to focus on health and function, as well as community participation as distinct life domains. Without health and function, individuals with disabilities are less likely to participate in the community and gain employment. In the past NIDRR has appropriately recognized that there are many instances in which meaningful improvements in health and function may not always translate directly into changes in vocational outcomes. It is important that NIDRR stimulate innovations and advance public policy on all three major life domains.

Infants, children, adolescents, and the elderly, as well as working age Americans with disabilities must benefit from the research and development activities conducted by NIDRR. NIDRR should reaffirm its longstanding recognition that rehabilitation is not limited to short-term engagement for those individuals experiencing injuries or illnesses, but also includes ongoing management of chronic conditions as people move through their lives. NIDRR must maintain a broad portfolio of disability and rehabilitation research that, in the words of the Rehabilitation Act, is designed to maximize the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities of all ages.

In order to fully and faithfully carry out NIDRR's mission, I urge the new Assistant Secretary for Special Education and Rehabilitative Services and the Director of NIDRR to restore the broad focus of NIDRR's research and development activities by recognizing the critical importance of all major life domains affecting persons with disabilities, i.e., Health and Function, Participation, as well as Employment.

CONTRIBUTOR: John D. Corrigan, Ph.D.
Ohio State University Medical Center
corrigan.1@osu.edu

DCN: 333

RECEIVED: 3/10/2009

COMMENT: With great interest I read the comments regarding the NIDRR proposed long-range plan for FYs 2010-2014 on the Web site. Most experts agree that the focus on employment is too narrow and that broader issues in terms of health, functioning and community participation should be addressed. Reflecting on these comments and recognizing that change will occur in the near future in particular in demographics and in the US health care system, my comments as an occupational therapist and as a scholar in public health and rehabilitation are as follow.

In line with the NIDRR mission statement, the focus should be inclusive in regard to all individuals with disabilities (all ages, ethnic groups, veterans) and all rehabilitation specialists (incl. medical/rehabilitation professionals, social workers, therapists, rehab engineers). NIDRR should advance knowledge that goes beyond identifying factors that serve as facilitators or barriers to demonstrate outcomes by supporting bold innovative research projects which can be sustained and replicated. All projects should be based on sound models and/or strategic approaches. Researchers should be encouraged to apply the ICF framework. More specifically I have three broad recommendations.

1. NIDRR invites researchers to conduct evidence-based clinical research which is transparent and multidisciplinary. High priority will be given to research applying and testing ICF core sets e.g., the Depression, Diabetes, Chronic conditions, Low Back, Obesity, Stroke, Osteoarthritis, TBI core sets. In addition, research investigating the role(s) of the (family) caregiver(s) in rehabilitation is strongly encouraged.
2. In fulfilling its role to support activities that increase self advocacy (the term self-determination used in the Notice, in my view, is out of date) and social participation, NIDRR supports participatory action strategic approaches to enhance accessibility for and opportunities by people with disabilities in community social life, recreation, leisure, arts and culture, religion and spirituality, human rights, equal opportunities (e.g., employment and volunteer work), and political life.
3. NIDRR enhances innovative research to better understand social change. For instance, interventions to explore the extent of awareness of disability issues among policymakers, business owners, managers of health and fitness centers, arts and culture venues and how physical and attitudinal environmental barriers can be removed. This is in particular critical for the growing number of elderly in our society who can and want to engage in many aspects of the community.

Thank you for the opportunity for sharing my comments.

CONTRIBUTOR: Els R. Nieuwenhuijsen, Ph.D., MPH, OTR
University of Michigan
elsrn@umich.edu

DCN: 334

RECEIVED: 3/10/2009

COMMENT: As a NIDRR-funded researcher for the last six years, I read the proposed long range plan for FY 2010-2014 with grave concern. It is clear from the language contained in this document that NIDRR intends to shift its research focus toward employment outcomes, seemingly at the expense of research addressing health and function, and participation and community living. This re-direction of resources is both untimely and unsettling to those of us who have depended on NIDRR to support high-quality research aimed at improving health and function en route to community reintegration.

From a personal perspective, my NIDRR-funded clinical trial of amantadine hydrochloride (H133A031713) involving individuals with severe TBI (one of the largest RCT's conducted to date in neurorehabilitation), and our functional neuroimaging work (H133A070030), have effectively directed attention to the needs of this marginalized population and led to novel findings that have forced a re-conceptualization of the core problems underlying the functional disabilities experienced by these individuals. Under the proposed LRP, it seems unlikely that NIDRR will continue to support scientific inquiry in this area, as restoration of employment is clearly not a primary objective of this line of research.

It is with great fondness and deep respect that I ask NIDRR to re-consider its apparent de-emphasis of research in health and function so that the momentum gained in this area over the last five years may be sustained, if not accelerated.

CONTRIBUTOR: Joseph T. Giacino, Ph.D.
American Congress of Rehabilitation Medicine
JGiacino@solarishs.org
(732) 321-7000 (x65871)

DCN: 335

RECEIVED: 3/11/2009

COMMENT: I am writing on behalf of myself and several other researchers at Rancho Los Amigos National Rehabilitation Center regarding NIDRR's proposed Long-Range Plan, 2009-2014. We are very disappointed to see that all outcomes of research must have an impact directly on vocational outcomes. We believe this is not a good plan to assist the population of people with disabilities who need the assistance from research that NIDRR can provide so uniquely. First, it ignores the needs of people who are either beyond the age of employment or are too young for employment. Many issues concerning older people and people aging with a disability occur after the age of 55. We have found in our research that people which have a disability are commonly retiring around this age but still have substantial issues interfering with their independence and quality of life. Likewise, young children, not yet ready for the work-world, have a great many needs for rehabilitation research that may or may not have an impact on their employment. Further, a five year grant would not be long enough to determine whether new discoveries and new innovations that are provided to a preschooler would have any effect on their vocational life. However, there are great needs for continued research on topics such as communication aids, mobility, social integration, and parenting issues. Also, there are many disabling conditions which put an end to employment most of the time but which still require further research. Examples here include major stroke, ALS, mid-life blindness, and brain injury.

We would like to see NIDRR withdraw the current plan and reformulate it to include vocational outcomes but other outcomes as well including improvements in independence, daily functioning, social participation, and quality of life. We look forward to working with you on a new and revised plan.

CONTRIBUTOR: Bryan Kemp, Ph.D.
bkemp@usc.edu

DCN: 336

RECEIVED: 3/11/2009

COMMENT: I have major concerns regarding the unbalanced emphasis in the 2010-14 Long Range Plan on employment for individuals who are disabled.

We are currently in an economic crisis in this country; it was probably not foreseen when the Long Range Plan was developed. Over the next 5 years we will be fortunate to avert unemployment rates that match those of the Great Depression of the last century. From this standpoint alone, it is a terrible time to be focusing so much on employment when the outcomes are going to be influenced by the background economic problems.

Another of our nation's challenges is minimizing health care costs. Individuals with disabilities need health care usually to a greater extent than their age counterparts without disabilities. The long range plan notes our aging population, both those currently with disability and those yet to have disabilities. Our aging populations, especially those with disabilities, are typically not focusing on return to work. They are trying to minimize their disability to lessen their health care costs and their burdens on caregivers/ families.

Young people with severe disabilities (brain injuries, strokes, spinal cord injuries, multiple sclerosis) are first and foremost trying to achieve the best health possible and re-integrate or remain integrated with their communities so that they are not socially isolated. A small portion of those with severe disabilities may be able to return to employment in good economic times; a much smaller percentage will be able to achieve this in economic hard times. Under NIDRR funding from 1987-92, we published a study of individuals with mild traumatic brain injury (TBI) and their outcomes at 3 months post injury. Almost 2/3 of those who were previously working were back at work without vocational intervention; this was much better than a study done a decade earlier that noted less than 1/3 had RTW (Englander J, Hall, K, Stimpson T, MS, CRC, Chaffin S: Mild Traumatic Brain Injury in an Insured Population: Subjective Complaints and Return to Employment, Brain Injury 1992 6:161-166). The economy of the late 1980's/ early 1990's was much stronger than the previous decade. My point is that the success of RTW outcomes is dependent on the overall employment level in the county more than any specific interventions.

Despite the advances of the ADA and the Kennedy-Jeffords initiative over the last 15 years, it is still very difficult for individuals with severe disabilities to retain their personal care attendant benefits while pursuing new employment possibilities. We have personal experience in our grant of hiring an individual as our peer support coordinator who requires these services in order to live every day and to work. It took him over 6 months to insure that he would not lose his benefits AFTER we offered him a position. We were patient and waited the 6 months; very few employers will do this, certainly not now when they can hire someone else right away. Our system for protecting these benefits, although better than 20 years ago, is still inadequate for the person seeking employment today.

NIDRR would be wise to broaden its focus to emphasize health and function, community participation and access as much as employment, especially in these very challenging economic times. Health and function and community participation are worthy ends in and of themselves, as the person with a disability who is healthier participates more in community activities (educational, vocational or volunteer) and spend less time ill in health care institutions and be less of a burden on caregivers, who can remain productive for longer periods of time. NIDRR sponsored research can help us learn as many ways as possible to keep individuals with disabilities healthy and in the community so that their direct health care costs and their indirect care costs are minimized.

CONTRIBUTOR: Jeffrey Englander, M.D.
Santa Clara Valley Medical Center
jeffery.englander@hhs.sccgov.org
(408) 885-2000

DCN: 337

RECEIVED: 3/11/2009

COMMENT: We are writing in response to the National Institute on Disability and Rehabilitation Research (NIDRR) Notice of Proposed Long-Range Plan for Fiscal Years 2010-2014. The proposed 2010-2014 Plan focuses primarily on one research domain, employment. This represents a significant shift from NIDRR's 2005-2009 Long Range Plan, which placed equal emphasis on five research domains: employment; health and function; participation and community living; technology; and disability demographics. We believe that NIDRR's shifting of its research focus to emphasize primarily employment overlooks the impact and diminishes the role the other research domains, particularly health and function, have on achieving and maintaining employment in individuals with disabilities.

NIDRR has served as the nation's lead federal agency on rehabilitation and disability research. NIDRR is unique in that it recognizes the multifaceted nature of disability and maintains a broad portfolio of research as reflected in the 2005-2009 Long Range Plan. This research portfolio included the aforementioned five broad domains designed to enhance the quality of life of persons with disabilities. This approach is to be commended as it recognizes the critical interplay between medical rehabilitation research, health and functioning, and employment.

It is imperative that NIDRR continue to follow the pathway it has built over the last 3 decades. Importantly, the 2005-2009 Long Range Plan continued NIDRR research efforts developed under the 1999-2003 Long-Range Plan by continuing to emphasize the major research domains of employment, participation and community living, health and function, and technology, while elevating the area of disability demographics to a major domain to reflect and reinforce the importance of improved disability data for policy, service design, and future research initiatives. By placing primary emphasis on the domain of employment in the proposed 2010-2014 Long Range Plan, NIDRR is relegating participation and community living, health and function, technology, and disability demographics to minor domain status.

One of NIDRR's great strengths has been its holistic approach to individuals with disabilities. Importantly, improvements in health and function, technology, and community participation are all critical antecedents to employment. The very example provided by NIDRR in the Notice illustrates this point: a manual wheelchair user must be able to maintain good arm function to maintain mobility that may be needed for employment. Improving arm function and mobility will also assist the individual in other areas as well, including independent living and community participation. (p.2566) Much of what is known about the impact of upper limb overuse in manual wheelchair users comes from prior research from the NIDRR-funded Spinal Cord Injury Model System Centers. The Consortium guidelines on the Preservation of Upper Limb Function Following Spinal Cord Injury are an output from Dr. Michael Boninger and his NIDRR-funded collaborative project in SCI research. This very example illustrates the importance of all domains in rehabilitation research. Our organization consists of rehabilitation researchers, physicians, policy makers, and individuals with disabilities. We have seen first-hand the impact NIDRR-funded research has on individuals with disabilities and their families. We recognize the importance of improving employment outcomes for individuals with disabilities. However, we strongly urge NIDRR to also continue its research emphasis on health and function research, including medical rehabilitation research. To do otherwise would be short-sighted and could have dire consequences on employment outcomes and community participation in individuals with disabilities.

CONTRIBUTOR: John DeLuca, Ph.D., ABPP
Kessler Foundation Research Center
jdeluca@kesslerfoundation.net
(973) 324-3572

DCN: 338

RECEIVED: 3/11/2009

COMMENT: We believe that NIDRR'S Notice of proposed long-range plan is flawed by prescribing a narrow focus on only one area of research (i.e. employment). The proposal correctly recognizes NIDRR's unique role established by Congress to foster disability and rehabilitation research designed to enhance self-determination and participation in the home, community, and workplace. President Obama's four point Disability Agenda has also clearly supported the need for comprehensive, multiple foci to improve the lives of individuals with disabilities. His plan outlines the need for efforts designed to improve educational opportunities; restoring the ADA promoting health and mental health care; community living opportunities for individuals with disabilities, as well as /increasing employment (i.e: <http://www.whitehouse.gov/agenda/disabilities/>).

The multifaceted approach supported by President Obama's Disability Agenda is also echoed by NIDRR's constituencies. In anticipation of the development of the long range plan, NIDRR convened public hearings at a number of locations. These hearings were attended by both consumers and researchers who offered testimony about the importance of continuing a broad focus on health and function, employment, and community participation. In fact, several of the consumers who testified they could not participate in employment because of the functional limitations associated with their disability, but they valued research to improve quality of life, address issues around care giving, community support, and other variables.

Historically, NIDRR has effectuated its unique role by indeed focusing on three broad areas of research—health and function research, employment-related research, and research related to community participation. Contrary to congressional intent and longstanding policy and practice, the Notice of NIDRR's proposed long range plan materially departs from previous plans by focusing on one category of research (employment) rather than on all three areas of research (health and function, employment and community participation). It will take a concerted effort to restore the proper, longstanding balance in the type of disability and rehabilitation research that NIDRR supports.

The proposal correctly recognizes NIDRR's unique role to support activities designed to increase the self-determination and participation of individuals with disabilities in the home, community, and workplace. NIDRR accomplishes this role by funding disability and rehabilitation research that explores the interaction of individual characteristics and environmental factors and their effects on the participation of individuals with disabilities in these settings (home, community, and workplace). Thus, historically, NIDRR has supported a wide range of disability and rehabilitation research, including health and function research that enhances the functioning of individuals with disabilities to live more independently; employment-related research; and research related to enhanced community participation. This focus on three areas of research was described in great detail in the previous long range plans. Prior long range plans also highlighted NIDRR's focus on research and development projects to generate new knowledge, along with supporting knowledge translation and capacity building.

In contrast to previous long range plans, rather than focusing on three areas of research (health and function, employment, and community participation), the Federal Register Notice describes the need for an employment focus. NIDRR has responded to this need by making the improvement of employment outcomes the focus of its long-range plan for FYs 2010-2014. Consistent with this focus on employment, the proposal only makes passing reference to health and function research and, when mentioned, health and function research is primarily mentioned in the context of employment and employment outcomes. For example, the Notice describes the purpose of health and function research as critical antecedents to improved employment for individuals with disabilities. Under research and development the proposed long-range plan articulates the following goal advance knowledge related to disability and rehabilitation through research and development, with particular emphasis on improving employment and participation outcomes for individuals with disabilities. Objective 1.1 focuses on increasing knowledge of the factors that serve as facilitators or barriers to improved employment outcomes Objective 1.2 focuses on increasing knowledge of the health and function factors that serve as facilitators of or barriers to improved employment and participation outcomes.

As stated above, the references to non-employment related search, including health and function research is made almost reluctantly: NIDRR's commitment is to maintain a broad array of mandated programs. It should be noted that the TBI model systems program which we believe to be of critical importance, is a non-mandated/ non employment- oriented program and thus, may be in particular jeopardy. In addition, the link between each new priority it funds and employment outcomes is problematic with respect to the needs of

individuals across the lifespan. The needs of elderly individuals and children with disabilities, historically part of NIDRR's broad array of research and KT efforts, are not included in a perspective that maintains a uni-dimensional, primary focus on employment outcomes.

Lastly, the Long Range Plan does not acknowledge the importance of NIDRR's responsibilities to provide information, training and technical assistance on the Americans with Disabilities Act. NIDRR is specifically charged with carrying out these activities (29USC76). In omitting this responsibility it also provides no direction regarding:

1. how its technical assistance project (DBTAC-ADA Centers) will be managed;
2. how the necessary resources will be allocated; and
3. how the activities will be coordinated with other federal efforts on ADA implementation.

The ADA is complex significant legislation that is not easily understood by the general population and NIDRR must revise the LRP to include details regarding the requirements to provide ADA technical assistance.

In sum, contrary to congressional intent, constituency input, longstanding policy and practice, the Notice of NIDRR's proposed long range plan materially departs from previous plans by focusing on one category of research (employment) rather than on all three areas of research (health and function, employment and community participation); it narrows the population focus by omitting the needs of the elderly and children with disabilities and lastly omits its responsibilities to assist in the implementation of the ADA by not detailing requirements for technical assistance on the topic.

CONTRIBUTOR: Marianne Farkas, President
National Association of Rehabilitation Research and Training Centers
mfarkas@bu.edu

DCN: 339

RECEIVED: 3/11/2009

COMMENT: This is Thao Duong, M.D. and I am a physician practicing primarily brain injury rehabilitation at Santa Clara Valley Medical Center. I have a lot of concerns regarding the newly proposed and unbalance emphasis on employment for individuals who are disabled in the 2010-14 Long Range Plan.

With the current economic crisis in our country and the rising unemployment rate for those with or without disability, at this time and over the next 5 years, it may not be appropriate time to have primarily an employment focus as the outcomes are going to be influenced greatly by the background economic problems.

Young people with severe disabilities (brain injuries, strokes, spinal cord injuries, multiple sclerosis) are first and foremost trying to achieve the best health possible and re-integrate or remain integrated with their communities so that they are not socially isolated. A small portion of those with severe disabilities may be able to return to employment in good economic times; a much smaller percentage will be able to achieve this in economic hard times. The economy of the late 1980's/ early 1990's was much stronger than the previous decade. It is known that the success of return to work outcomes is greatly dependent on the overall employment level in the county more than any specific interventions.

An area that we may want to focus on might be minimizing health care costs. Individuals with disabilities, in general, need health care to a greater extent than the population without disabilities. The long range plan notes our aging population, both those currently with disability and those yet to have disabilities. Our aging populations, especially those with disabilities, are typically not focusing on return to work. They are trying to minimize their disability to lessen their health care costs and their burdens on caregivers/ families.

In addition, despite the advances of the ADA and the Kennedy-Jeffords initiative over the last 15 years, it is still very difficult for individuals with severe disabilities to retain their personal care attendant benefits while pursuing new employment possibilities. Our system for protecting these benefits, although better than 20 years ago, is still inadequate for the person seeking employment today.

NIDRR should broaden its focus to emphasize health and function, community participation and access as much as employment, especially in these very challenging economic times. Health and function and community participation are worthy ends in an of themselves, as the person with a disability who is healthier participates more in community activities (educational, vocational or volunteer) and spend less time ill in health care institutions and be less of a burden on caregivers, who can remain productive for longer periods of time. NIDRR sponsored research can help us learn as many ways as possible to keep individuals with disabilities healthy and in the community so that their direct health care costs and their indirect care costs are minimized.

Thank you for your consideration.

CONTRIBUTOR: Thao Duong, M.D.
Santa Clara Valley Medical Center
thao.duong@hhs.sccgov.org

DCN: 340

RECEIVED: 3/11/2009

COMMENT: Comments on the NIDRR Long Range Plan 2010-2014.

1. Previous NIDRR Long Range Plans included detailed, finely crafted analyses of the state of disability and rehabilitation research across the full range of the field. They also included plans to address those needs. Those documents were so inclusive and well written that they were often used as required reading in graduate courses in universities. The proposed LRP for 2010-2014, by contrast, is exceedingly brief and contains little information in most areas that would guide the development of priorities and the preparation of grant proposals.

We recommend that the proposed plan be expanded to provide a greater depth of analysis and a broader range of target areas.

2. The proposed LRP for 2010-2014 is out of balance with respect to the four distinct yet related areas of disability and rehabilitation research (health and function, employment, assistive technology and community integration). There is no basis in legislation or in logic for focusing the plan on employment research.

We recommend that balance be restored to the plan by providing equal importance to the different areas of disability and rehabilitation research.

CONTRIBUTOR: John Stone, Ph.D.
Center for International Rehabilitation Research Information and Exchange (CIRRIE)
jstone@buffalo.edu
(716) 829-6739

DCN: 341

RECEIVED: 3/12/2009

COMMENT: Our comment focuses on Objective 1.4: Increase understanding of the assistive technology and environmental factors that serve as facilitators of or barriers to improved employment and participation outcomes by supporting research and development on...

This objective is the only one concerned with assistive technology. It is gratuitously narrow by being limited to employment and participation outcomes, and it is manifestly incomplete. It overlooks themed to develop improved assistive technologies and environmental accommodations in the tradition of those summarized under NIDRR Accomplishments, p. 2565), and it ignores the concomitant need for outcomes-based knowledge about how well such technologies—both newly developed and already available ones—meet their users' needs.

We therefore recommend that Objective 1.4 be fundamentally revised. The revision should include focus on assistive technology outcomes research. That focus should be one of strengthening the scientific basis for understanding the impacts that assistive technologies and environmental accommodations have on the day-to-day functioning, health, and participation of users and their family members. The strategies needed to address this focus include:

- Improving methods for measuring assistive technology outcomes by evaluating the soundness of current measures and technologies for data capture and reporting, adding evidence about their reliability, validity, and usefulness, and by developing new measures and technologies that reflect the impacts of AT on participation in the home, community, school, and workplace.
- Making outcomes assessment integral to the R&D process by assessing newly developed assistive technologies and environmental modifications in terms of their impacts on users' day-to-day functioning, health, and participation.
- Conducting theoretically informed investigations of the outcomes attained by innovative approaches to AT services, including assessment, device selection, customization, training, and maintenance, as experienced by individuals with disabilities in all age groups.
- Conducting theoretically informed investigations that identify the interactions between assistive technology and personal assistance and their influence on the activities and participation of individuals with disabilities and of the caregivers who assist them.
- Conducting theoretically informed investigations that link the characteristics of assistive technology services as an intervention with the activity and participation outcomes of specific populations.
- Conducting theoretically informed investigations that identify assistive technology influence on the continued employment and participation of aging workers.

Rationale:

Sound outcomes information is required by all of the stakeholders involved in the provision of assistive technology and its use. Absent that information, candidate users, practitioners, and payers are forced to depend on the uncontested claims of manufacturers and vendors or the anecdotal reports of individual users. Efficacy trials are the exception rather than the rule for most technologies emerging from the development process. Instead, stakeholders are left with the assertions of developers or the word-of-mouth testimonials of selected users. That situation may be tolerable for simpler, relatively low-cost devices whose advantages are self-evident. It is decidedly problematic, however, for the technologically complex, highly expensive devices that continue to become available, examples being increasingly sophisticated powered wheelchairs, robotic aids, my electric prostheses, fabricated replicas of joints using biocompatible materials, adapted vehicles, and computerized environmental control systems. Dependable information regarding which technologies work, for whom, and why is indispensable as well for charting future research and development aimed at improving them.

The need for assistive technology outcomes information is compounded by the complexity of the services entailed in making the technology available to consumers. Those services may involve assessing candidates for their appropriateness to use the technology, adapting technologies to optimize their fit with users, training individuals in their use, and providing ongoing maintenance and repair. Failure at any one of those junctures can jeopardize outcomes as much as can bad design or shoddy manufacture. The inseparability of many assistive technologies from their service provision contexts introduces uncertainties about their outcomes

that are not readily offset by anecdotal evidence regarding their successes or failures. Historically, NIDRR-supported R&D has resulted in numerous innovative assistive technologies. Projects devoted to such innovations are prominent in NIDRR's current portfolio, especially within several of the Rehabilitation Engineering and Research Centers. This aggregate support far exceeds the investment in improving the quality and quantity of research for determining the outcomes of those innovations. That commitment is embodied currently in a single DRRP whose funding expires in FY2009. It is critical that the revised Long Range Plan legitimate future investments of that kind. Toward that end, we have highlighted an objective and an array of strategies that will advance assistive technology outcomes research by strengthening its methodological foundation and by addressing the substantive issues of greatest concern to stakeholders.

CONTRIBUTOR: Frank DeRuyter, Ph.D.
Duke University Medical Center
deruy001@mc.duke.edu
(919) 684-6271
Louise Demers, Ph.D.
Marcus J. Fuhrer, Ph.D.
Jeffrey Jutai, Ph.D.
James Lenker, Ph.D.

DCN: 342

RECEIVED: 3/12/2009

COMMENT: The purpose of this letter is to provide comments to the Assistant Secretary for Special Education and Rehabilitative Services on behalf of the undersigned members of the Disability and Rehabilitation Research Coalition (DRRC) regarding the proposed long range plan (FYs 2010-2014) for the National Institute on Disability and Rehabilitation Research (NIDRR).

Set out below is a summary of our comments followed by a more in depth recitation of our position. The in depth recitation includes a brief review of the historical and policy context of NIDRR, a statement of principles that guided our review of the proposal, and our recommendations regarding the LRP mission statement, the inclusion of a logic model, goals, outcomes, focus, operational performance measures, and research agenda.

SUMMARY OF COMMENTS

Since the U.S. Congress established The National Institute on Disability and Rehabilitation Research (NIDRR) in 1978, it has served as the flagship federal agency on disability and rehabilitation research. NIDRR is a mission-oriented agency-its mission is to explore the interaction of individual characteristics and environmental factors and their effects on the participation of individuals with disabilities of all ages in the home, community, school, and workplace. NIDRR carries out its mission by generating new knowledge through research and development, promoting its effective use (knowledge translation), and building the capacity of institutions and individuals to conduct high quality research and development.

In the two previous long-range plans covering FY1999 through the present, NIDRR has recognized that in order to carry out its mission, research and development activities must focus on three major life domains:

- Employment,
- Participation and community living; and
- Health and function (including medical rehabilitation interventions to improve function and health status research to improve overall health and wellness of people with disabilities).

In addition, NIDRR has recognized the need to focus on technology for access and function and disability demographics.

On January 15, 2009, five days before the inauguration of President Obama, the acting Assistant Secretary for Special Education and Rehabilitative Services published a notice in the Federal Register proposing a long range plan for NIDRR for Fiscal Years 2010-2014. The proposed plan modifies this longstanding focus on the major life domains of employment, participation and community living, and health and function and instead specifies that the improvement of employment outcomes [will be] the focus of its long range plan for FYs 2010-2014. [74 FR at page 2566] Thus, the focus of research and development activities relating to the life domains of participation and community living and health and function have been relegated to a less prominent status under the proposal, thereby undermining NIDRR's mission to improve participation of persons with disabilities of all ages in the home, community, school, as well as the workplace.

Consistent with the focus on employment, the proposal only makes passing reference to health and function research and, when mentioned, health and function research is primarily mentioned in the context of employment and employment outcomes. For example, the Notice describes the purpose of health and function research as critical antecedents to improved employment for individuals with disabilities. Under research and development the proposed long-range plan articulates the following goal advance knowledge related to disability and rehabilitation through research and development, with particular emphasis on improving employment and participation outcomes for individuals with disabilities. Objective 1.1 focuses on increasing knowledge of the factors that serve as facilitators or barriers to improved employment outcomes Objective 1.2 focuses on increasing knowledge of the health and function factors that serve as facilitators of or barriers to improved employment and participation outcomes. [74 FR at pages 2566-2567]

As stated above, the references to non-employment related research; including health and function research is made almost reluctantly:

NIDRR proposes to use the goals, objectives and strategies described in the following section to guide the development of grant priorities in the coming years. Focusing the Plan on employment and employment outcomes will not prevent NIDRR from continuing the work it is currently funding. NIDRR will maintain a broad array of mandated programs it currently supports (e.g., the rehabilitation engineering research centers

and spinal cord injury model systems program) and, where possible, will establish a link between each new priority it funds through these programs and employment outcomes.

We believe that there is a continuing need for NIDRR to recognize and focus on health and function as a distinct life domain. Without health and function, individuals with disabilities are less likely to participate in the community and employment. In the past NIDRR has appropriately recognized that there are many instances in which meaningful improvements in health and function may not always translate directly into changes in vocational outcomes. We also believe that there is a continuing need for NIDRR to recognize and focus on participation and community living as a distinct life domain.

So there is no misunderstanding about the position of the undersigned organizations regarding the appropriate focus of NIDRR's research and development activities, we want to make it perfectly clear that we also fully support research and development activities that focus on employment. It is critical for NIDRR to advance employment-related innovations (both demand and supply side), improve delivery of services at the systems level (with particular emphasis on improving the effectiveness of services authorized under the Rehabilitation Act), and advance public policy that makes work pay (work incentives and the seamless delivery of services and supports). What we are saying is that if NIDRR is to accomplish its congressionally-mandated mission, it must continue the longstanding policy of focusing its research and development activities on all major life domains, including participation and community living, health and function, as well as employment.

Infants, children, adolescents, and the elderly, as well as working age Americans with disabilities must benefit from the research and development activities conducted by NIDRR. NIDRR should reaffirm its longstanding recognition that rehabilitation is not limited to short-term engagement for those individuals experiencing injuries or illnesses, but also includes ongoing management of chronic conditions as people move through their lives. NIDRR must maintain a broad portfolio of disability and rehabilitation research that, in the words of the Rehabilitation Act, is designed to maximize the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities of all ages.

In order to fully and faithfully carry out NIDRR's mission, we urge the new Assistant Secretary for Special Education and Rehabilitative Services and the Director of NIDRR to restore the broad focus of NIDRR's research and development activities by recognizing the critical importance of all major life domains affecting persons with disabilities, i.e., participation and community living, health and function, as well as employment.

IN DEPTH RECITATION OF COMMENTS

HISTORICAL AND POLICY CONTEXT

Historically, Congress established NIDRR to serve as the Nation's lead federal agency on rehabilitation and disability research and, as such, to maintain a broad portfolio of research designed to maximize the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities of all ages. [See, Section 200 of the Rehabilitation Act of 1973, as amended] Since 1978 and in the two most recent long-range plans, NIDRR has recognized that its mission is to generate new knowledge and promote its effective use to improve the abilities of people with disabilities to perform activities of their choice in the community, and also to expand society's capacity to provide full opportunities and accommodations for its citizens with disabilities. NIDRR also has recognized the substantive focus of its investment in Research and Development related to maximizing the participation of people with disabilities. More specifically, research and development activities are centered on the three major life domains of interest to NIDRR:

- Employment;
- Participation and community living; and
- Health and function.

[See, 71 Federal Register at page 8173] The U.S. Department of Education's Strategic Plan for Fiscal Years 2007-12 reaffirms the Department's obligations to fulfill its congressional mandate to continue to support and monitor research leading to the development of interventions that support health and physical function, participation and integration into the community, and employment of individuals with disabilities. [See, Page 31, emphasis added]

In sum, Congress directed NIDRR to serve as the lead and primary agency to conduct disability and rehabilitation research related to employment and participation and integration into the community. Congress

also directed NIDRR to serve as the lead and primary agency supporting medical rehabilitation research that enhances the health and function of people with disabilities i.e., research designed to enhance treatments that allow persons with traumatic brain injury, spinal cord injury, and other impairments to more fully participate in activities of daily living and be part of society. If we are to achieve the promises of the Americans with Disabilities Act, Congress expects NIDRR to lead the way in learning about new and better strategies to the improve community integration, health and function as well as the employment of people with disabilities.

Consistent with Congressional intent, NIDRR historically has recognized that there are many instances in which meaningful improvements in participation and community integration may not always translate directly into vocational outcomes, especially for infants, children and adolescents and older Americans who are not working. NIDRR also has recognized that there are many instances in which meaningful improvements in health and function may, but do not always translate directly into changes in vocational outcomes. The continuing need for medical rehabilitation research is to improve function and the need for health status research is to improve overall health and wellness of persons with disabilities. Without health and function, individuals with disabilities are less likely to participate in the community and in employment. Indeed, good health and function are essential to the achievement of these other very important goals.

Based on our understanding of congressional intent, as reflected in our review of NIDRR's historical and policy context, we have developed a set of principles to help guide the development of our comments regarding the content of NIDRR's new LRP.

NIDRR's new LRP should:

- Reflect NIDRR's history and policy designating NIDRR as the lead federal agency on rehabilitation and disability research and NIDRR's need to maintain a broad portfolio of research;
- Embrace the breadth and depth of critical domains impacting the lives of persons with disabilities (employment, participation and community living, and health and function);
- Address the needs of persons with disabilities of all ages, including infants, children, adolescents, older Americans as well as individuals of working-age;
- Recognize that rehabilitation is not only an intervention designed to fix someone who has been injured but includes ongoing management of chronic conditions;
- Build on NIDRR's current LRP;
- Include a Logic Model to help select those research activities to be supported that are most likely to lead to intermediate and long-term outcomes of interest;
- Build on the strong history of research accomplishments in all critical life domains; and
- Insist on the use of management strategies, including high-quality peer review, that result in support of rigorous research that is of utility to stakeholders.

MISSION

Consistent with Title II of the Rehabilitation Act, we recommend that NIDRR's new LRP include the following mission statement:

The mission is to generate new knowledge and promote its effective use to improve the abilities of people with disabilities of all ages to perform activities of their choice in the home, community, school, and workplace and also to expand society's capacity to provide full opportunities and accommodations for its citizens with disabilities.

LOGIC MODEL

We recommend that NIDRR's new LRP recognize that significant gaps exist in knowledge, skills, policy, practice, and system capacity that prevent people with disabilities from having equal access to opportunities for employment, participation and community living, and health and function. The substantive focus of NIDRR's investment activity should be centered on the three major life domains of interest to NIDRR-employment, participation and community living, and health and function. In addition, the Logic Model should include two additional domains-technology for access and function and disability demographics.

With respect to employment, for many people with disabilities, employment that is challenging, fulfilling, and adequately compensated is the ultimate rehabilitation outcome. Employment shapes the lives of individuals with disabilities who are interested in and qualified for workforce participation. At the individual and systems level success should be measured in terms of acquisition, improvement, and enhancement of skills,

productivity, earnings, job retention and advancement, and benefits. NIDRR should advance employment-related innovations that contribute to success at work and subsequent improvements in quality of life in education, home, and community. Research supported by NIDRR must continue to focus on improving the implementation of employment-related activities supported by OSERS, including the Rehabilitation Services Administration (RSA).

With respect to participation and community living, NIDRR should focus on the extent to which people with disabilities are participating in the community in a manner that is meaningful to them and support research into programs and services that expand the scope of participation of people with disabilities, especially those with the most severe disabilities. NIDRR should sponsor research to improve knowledge of individual and societal level factors that may serve as barriers to, or facilitators of, participation among all people with disabilities. Research may include evaluation of specific participation-promoting programs, interventions and products, as well as development of methods, measures, and theories to enhance scientific rigor of these evaluations.

With respect to health and function, research on maximizing health and function among people with disabilities is critical to the achievement of NIDRR's mission and the associated higher-order goals of employment and community participation. Functional ability reflects the complex interaction between individuals and the environments in which they live. In conceptualizing health and function research to improve the lives of individuals with disabilities, NIDRR should posit a growing need for research on medical rehabilitation interventions to improve function and for health status research to improve overall health and wellness of people with disabilities.

GOALS

The LRP should identify strategic goals that communicate NIDRR's main themes and directions. The goals should reflect NIDRR's mission and align with the targeted outcomes arenas depicted in the Logic Model. We recommend that NIDRR's new LRP include the following four goals:

- Research and Development (R & D)-Advance knowledge about disability and rehabilitation through research and development.
- Knowledge Translation (KT)-Increase the use of research and development knowledge to improve policy, practice, behavior and systems related to disability and rehabilitation.
- Capacity Building (C-B)-Increase the capacity of individuals (particularly those with disabilities) and institutions to conduct high-quality disability and rehabilitation research and development.
- Management-continuously improve NIDRR outcomes through effective management, monitoring and use of program data.

OUTCOMES

Long-term outcomes arenas. NIDRR's long-term outcomes should focus on eliminating disparities between people with and without disabilities in employment, participation and community living, and health and function. These long-term outcomes should serve as critical anchor points guiding all strategic planning and research management efforts.

Short-term outcomes arenas. Within the logic model, there should be four short-term outcome arenas corresponding to NIDRR's investments in four functional arenas. These functional arenas are R&D, KT, C-B, and management corresponding to NIDRR's four strategic goals. R&D should be further divided to reflect three stages of knowledge development-

1. discoveries;
2. new or improved theories, measures, or methods; or
3. interventions, products, devices, and environmental adaptations.

FOCUS

At the heart of NIDRR's mission should be the support of research to improve the lives of people with disabilities. We recommend that NIDRR's new LRP focus attention on the major life domains as set out in the Logic Model. Improving employment outcomes should be a major concern of NIDRR as should improving the functioning of OSERS' programs related to employment, including vocational rehabilitation and programs related to the education of transition-age youth with disabilities. Similarly, improving participation and community living outcomes (including maximizing choices for persons with disabilities as they select their dwellings, transportation, and life activities) should be a major concern of NIDRR. Furthermore, improving health and function outcomes should be a major focus of NIDRR research as advances in this domain are

the foundation for attaining outcomes related to employment and participation and community living.

OPERATIONAL PERFORMANCE MEASURES

The future research agenda for NIDRR should rest on the long-term outcomes depicted in the Logic Model, which call for the elimination of disparities in employment, increasing participation and community living, and improving health and function for people with disabilities and the general population. However, because achieving this desired end-result requires changes in the overall condition of people with disabilities that go beyond the reach of the Institute's mission, it is necessary to articulate an additional set of more operational performance measures with respect to employment, participation and community living, and health and function.

RESEARCH AGENDA

The research agenda, as we suggested, must reflect the three critical life domains of individuals with disabilities-employment, participation and community living, and health and function. The proposed LRP focuses on the research agenda related to the employment domain. Set out below are our comments regarding the participation and community living and health and function domains.

NIDRR's research agenda in the domain of participation and community living should be designed to strengthen the scientific basis of policies and practices aimed at enhancing participation among people with disabilities by providing information and analyses that improve understanding of participation levels among individuals with disabilities and the multiple barriers and facilitators of their participation. NIDRR's research agenda should also strengthen participation-related research and practice by increasing the availability of validated theories, measures, and methods. These theories, measures, and methods should improve data sources and estimates, and should enable better identification, evaluation, and prediction of the factors that facilitate or impede participation and community living. These improvements should enhance the credibility of research and thus increase the utilization of research findings.

As stated above, maximizing health and function of people with disabilities is critical to the achievement of community participation and employment. Functional ability reflects the complex interaction between individuals and the environment in which they live. Accordingly, NIDRR should conceptualize and examine issues of health and function at both the individual and systems levels.

Specifically, the health and function agenda at the individual level should fund research that supports the development and evaluation of new interventions, products, devices, and environmental adaptations aimed at improving the health status and functional abilities of people with a wide range of disabling conditions. These interventions should address the needs of people who are aging with disability, with particular emphasis on minimizing secondary health conditions and disabilities. These interventions should also address the unique needs of infants, children and adolescents with disabilities. NIDRR should also fund research that leads to the development of the next generation of valid and reliable measures of health and functional status among people with disabilities.

At the systems level, NIDRR-supported research should focus on the structure, organization, and delivery of health care and medical rehabilitation services. Also at the systems level, NIDRR should study access to health care and rehabilitative services, and the complex delivery systems used for those services. Individual level research should focus on the development and testing of new interventions that improve functional and health outcomes for individuals. As already stated, in conceptualizing health and function research to improve the lives of individuals with disabilities, NIDRR should posit a growing need for research on medical rehabilitation interventions to improve function and for health status research to improve overall health and wellness of people with disabilities.

At the systems level, NIDRR should also fund research that will generate new knowledge about the systematic causes and consequences of substandard access to rehabilitation, healthcare, and mental health care services for people with a wide range of disabling conditions. This research will identify and evaluate the effectiveness of specific service delivery approaches and payment models aimed at minimizing physical, social, and economic barriers to the full spectrum of health, mental health, and rehabilitation services that are needed by people with disabilities. In addition, research is needed to support the development of evidenced-based practice methods that are consistent with rehabilitation treatment practices that currently exist in the field and with the rehabilitation research methods used to develop new assessments and interventions.

Overall Agenda-NIDRR's research agenda in the area of health and function should be designed to increase the number of validated new or improved methods for assessing function and health status; increase the number of interventions, products, and devices demonstrated to be efficacious in improving health and

function outcomes in targeted disability populations; and increase understanding of the underlying structures and processes that facilitate or impede equitable access to rehabilitation and physical and mental healthcare by people with disabilities.

Thank you for this opportunity to submit comments to NIDRR's next Long Range Plan. If you have any questions, please feel free to contact Robert Bobby Silverstein (202)-466-6550; Bobby.Silverstein@ppsv.com or Peter Thomas (202) 466-6550; Peter.Thomas@ppsv.com.

CONTRIBUTOR: Anthony Chen, M.D.
University of California, San Francisco
anthony_chen@sbcglobal.net

DCN: 343

RECEIVED: 3/12/2009

COMMENT: On behalf of the Brain Injury Association of America (BIAA) and the 1.4 million Americans who sustain a traumatic brain injury (TBI) each year, I am writing to express my deep concern regarding the proposed long range plan (FYs 2010-2014) for the National Institute on Disability and Rehabilitation Research (NIDRR). As proposed, NIDRR's plan will all but abandon the agency's longstanding commitment to research in the life domains of health and function as well as participation and community living, and instead, narrowly focus on employment. In general, BIAA believes such an approach would undermine NIDRR's mission to improve participation of persons with disabilities of all ages in varied settings. Specifically, BIAA believes the proposed approach would have long-lasting, detrimental effects on individuals with brain injury.

For people with brain injury, health and function research (including medical rehabilitation interventions) is more than an antecedent to employment. Indeed, the knowledge stemming from the health and function portion of NIDRR's research portfolio is vital to maintaining the overall health and wellness of individuals with brain injury and to maximizing their independence. Moreover, while such interventions do not always translate directly into changes in vocational outcomes, they do reduce dependency on public health and welfare systems and contribute significantly to the body of knowledge on TBI.

For example, the NIDRR's TBI Model Systems are the only source of non-proprietary longitudinal data on what happens to people with brain injury immediately after the injury and throughout their lifetimes. The Model Systems are a key source of evidence-based medicine, and serve as a proving ground for future researchers. TBI Model Systems researchers are currently working closely with the Department of Veterans Affairs to improve the treatment of returning service members with brain injuries.

Brain injury is not an event or an outcome. It is the beginning of a lifelong disease process. NIDRR should reaffirm its longstanding recognition that rehabilitation is not limited to short-term engagement for those individuals experiencing injuries or illnesses, but also includes ongoing management of chronic conditions as people move through their lives. NIDRR must maintain a broad portfolio of disability and rehabilitation research, including TBI-related Rehabilitation Research and Training Centers (RRTC's) and field-initiated investigations, which make similar contributions to ensuring the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with TBI, regardless of age.

In order to fully and faithfully carry out NIDRR's mission, the Brain Injury Association of America strongly urges the new Assistant Secretary for Special Education and Rehabilitative Services and the Director of NIDRR to restore the broad focus of NIDRR's research and development activities by recognizing the critical importance of all major life domains affecting persons with disabilities, i.e., participation and community living, health and function, as well as employment.

CONTRIBUTOR: Susan H. Connors
Brain Injury Association of America
sdorsie@biausa.org
(703) 584-8637

DCN: 344

RECEIVED: 3/12/2009

COMMENT: On behalf of the Brain Injury Association of New Mexico (BIA NM) and the 1.4 million Americans who sustain a traumatic brain injury (TBI) each year, I am writing to express my deep concern regarding the proposed long range plan (FYs 2010-2014) for the National Institute on Disability and Rehabilitation Research (NIDRR).

As proposed, NIDRR's plan will all but abandon the agency's longstanding commitment to research in the life domains of health and function as well as participation and community living, and instead, narrowly focus on employment. In general, BIAA believes such an approach would undermine NIDRR's mission to improve participation of persons with disabilities of all ages in varied settings. Specifically, BIAA believes the proposed approach would have long-lasting, detrimental effects on individuals with brain injury.

For people with brain injury, health and function research (including medical rehabilitation interventions) is more than an antecedent to employment. Indeed, the knowledge stemming from the health and function portion of NIDRR's research portfolio is vital to maintaining the overall health and wellness of individuals with brain injury and to maximizing their independence. Moreover, while such interventions do not always translate directly into changes in vocational outcomes, they do reduce dependency on public health and welfare systems and contribute significantly to the body of knowledge on TBI.

For example, the NIDRR's TBI Model Systems are the only source of non-proprietary longitudinal data on what happens to people with brain injury immediately after the injury and throughout their lifetimes. The Model Systems are a key source of evidence-based medicine, and serve as a proving ground for future researchers. TBI Model Systems researchers are currently working closely with the Department of Veterans Affairs to improve the treatment of returning service members with brain injuries.

Brain injury is not an event or an outcome. It is the beginning of a lifelong disease process.

NIDRR should reaffirm its longstanding recognition that rehabilitation is not limited to short-term engagement for those individuals experiencing injuries or illnesses, but also includes ongoing management of chronic conditions as people move through their lives. NIDRR must maintain a broad portfolio of disability and rehabilitation research, including TBI-related Rehabilitation Research and Training Centers (RRTC's) and field-initiated investigations, which make similar contributions to ensuring the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with TBI, regardless of age.

In order to fully and faithfully carry out NIDRR's mission, the Brain Injury Association of New Mexico strongly urges the new Assistant Secretary for Special Education and Rehabilitative Services and the Director of NIDRR to restore the broad focus of NIDRR's research and development activities by recognizing the critical importance of all major life domains affecting persons with disabilities, i.e., participation and community living, health and function, as well as employment.

CONTRIBUTOR: Clara Holguin
Brain Injury Association of New Mexico
claraholguin@msn.com
(505) 292-7414

DCN: 345

RECEIVED: 3/12/2009

COMMENT: On behalf of the Brain Injury Association of Vermont (BIAVT) and the 1.4 million Americans who sustain a traumatic brain injury (TBI) each year, I am writing to express my deep concern regarding the proposed long range plan (FYs 2010-2014) for the National Institute on Disability and Rehabilitation Research (NIDRR). As proposed, NIDRR's plan will all but abandon the agency's longstanding commitment to research in the life domains of health and function as well as participation and community living, and instead, narrowly focus on employment. In general, BIAA believes such an approach would undermine NIDRR's mission to improve participation of persons with disabilities of all ages in varied settings. Specifically, BIAA believes the proposed approach would have long-lasting, detrimental effects on individuals with brain injury.

For people with brain injury, health and function research (including medical rehabilitation interventions) is more than an antecedent to employment. Indeed, the knowledge stemming from the health and function portion of NIDRR's research portfolio is vital to maintaining the overall health and wellness of individuals with brain injury and to maximizing their independence. Moreover, while such interventions do not always translate directly into changes in vocational outcomes, they do reduce dependency on public health and welfare systems and contribute significantly to the body of knowledge on TBI.

For example, the NIDRR's TBI Model Systems are the only source of non-proprietary longitudinal data on what happens to people with brain injury immediately after the injury and throughout their lifetimes. The Model Systems are a key source of evidence-based medicine, and serve as a proving ground for future researchers. TBI Model Systems researchers are currently working closely with the Department of Veterans Affairs to improve the treatment of returning service members with brain injuries.

Brain injury is not an event or an outcome. It is the beginning of a lifelong disease process. NIDRR should reaffirm its longstanding recognition that rehabilitation is not limited to short-term engagement for those individuals experiencing injuries or illnesses, but also includes ongoing management of chronic conditions as people move through their lives. NIDRR must maintain a broad portfolio of disability and rehabilitation research, including TBI-related Rehabilitation Research and Training Centers (RRTC's) and field-initiated investigations, which make similar contributions to ensuring the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with TBI, regardless of age.

In order to fully and faithfully carry out NIDRR's mission, the Brain Injury Association of Vermont strongly urges the new Assistant Secretary for Special Education and Rehabilitative Services and the Director of NIDRR to restore the broad focus of NIDRR's research and development activities by recognizing the critical importance of all major life domains affecting persons with disabilities, i.e., participation and community living, health and function, as well as employment.

CONTRIBUTOR: Trevor J. Squirrell
Brain Injury Association of Vermont
tsquirre@sover.net
(877) 856-1772

DCN: 346

RECEIVED: 3/16/2009

COMMENT: First, thank you for the long range plan review for NIDRR. Medgraph has reviewed the plan and totally supports the plan implementation.

Medgraph continues to research and develop new hardware, software and systems for healthcare communications for the disabled and disadvantaged.

NIDRR supported research has enabled system advancements for hearing, visually and cognitively impaired healthcare communications systems. Our research continues to indicate a strong need for better health literacy in the disadvantaged and disabled populations. New educational tools are essential for the underserved disadvantaged and disabled populations. This population is not being served by the current communications mechanisms and advancements are required to improve employment, school attendance and increase mobility.

Medgraph is passionate and dedicated to advancing knowledge in these areas and we look forward to a continued and expanding interaction with NIDRR.

CONTRIBUTOR: Ed Schlueter
Medgraph, Inc.
eds@med-graph.com

DCN: 347

RECEIVED: 3/16/2009

COMMENT: I am writing this letter in response to the National Institute on Disability and Rehabilitation Research (NIDRR) Notice of Proposed Long-Range Plan (LRP) for Fiscal Years 2010-2014. The proposed 2010-2014 Plan shifts the emphasis from a diverse research agenda to primarily one research domain, employment. NIDRR's previous Long Range Plans have prioritized several research areas including: employment; health and function; participation and community living; technology; and disability demographics. The proposed research focus in the LRP 2010-2014, emphasizes employment as the primary domain. This emphasis will cause a major break in the tradition of NIDRR research funding. It will serve to diminish the amount of research in other important research domains (e.g., particularly health and function, community participation, and technology). NIDRR has built capacity over the last thirty years and I fear that this proposed LRP will serve to dismantle some key capacities that have been developed over years. Finally, and most important, this proposed LRP will have a detrimental effect on the quality of life of individuals living with disabilities.

NIDRR has been the only federal research funding agency that has supported rehabilitation research designed to improve the quality of life of individuals with disabilities. The balanced, diverse approach of focusing on diverse research areas has been an important component of NIDRR's mission. NIDRR has served as the nation's lead federal agency on rehabilitation and disability research and its contribution has been unique. NIDRR has traditionally focused on the multifaceted nature of disability. Its broad and diverse portfolio of research, as reflected in the 2005'09 Long Range Plan, served to improve the quality of life of individuals with disability. This included research priorities in the areas of Health and Function, Community Participation, Employment, Technology, Disability Demographics. Additionally, NIDRR funding has served to improve the rehabilitation research infrastructure and funded such areas as outcomes measurement and disability demographics. In essence, NIDRR has been a critical agency and has helped improve the quality of research conducted throughout the rehabilitation field. This approach is to be commended as it recognizes the critical interplay between medical rehabilitation research, health and functioning, integration into the community, and employment.

It is imperative that NIDRR follow the pathway it has built over the last 3 decades. I would strongly encourage the NIDRR leadership to modify the proposed 2010-2014 Long Range Plan so that NIDRR's research efforts will include a more diversified, multi-faceted agenda prioritizing research domains of employment, participation and community living, health and function, and technology in equal standing. Additionally, elevating the areas of disability demographics and outcomes measurement to major domains will also reflect and reinforce the importance of improved disability data and assessment for policy, service design, and future research initiatives.

One of NIDRR's great strengths has been its holistic approach to individuals with disabilities. Importantly, improvements in health and function, technology, assessment, and community participation are all critical antecedents to the improvement of the quality of life for individuals with disabilities. While I recognize the importance of improving employment outcomes for individuals with disabilities, I also view these other areas as equally important. For this reason, I strongly urge NIDRR to revise the proposed LRP and continue its research emphasis on health and function, community participation, technology, outcomes measurement, and disability demographics research. This agenda should include applied medical rehabilitation research. To do otherwise would be short-sighted and could have dire consequences on improving the quality of life for individuals with disabilities.

CONTRIBUTOR: David S. Tulsky, Ph.D.
Kessler Foundation Research Center
dtulsky@kesslerfoundation.net
(973) 243-6977

DCN: 348

RECEIVED: 3/16/2009

COMMENT: We are writing in response to the call for comments on the proposed National Institute on Disability and Rehabilitation Research (NIDRR) Long-Range Plan (Plan) for fiscal years 2010-2014. The Research Council of TIRR Memorial Hermann (TIRR) commends NIDRR as the leader in federally funded applied rehabilitation research for persons with disabilities. Programs funded by NIDRR have made enormous contributions to the health and function, employment, and community participation outcomes of persons with disabilities. Our institute has participated in the Spinal Cord Injury Model Systems program, the Traumatic Brain Injury Model Systems program, and the Disability Business Technical Assistance Center since their beginnings. We have also housed several Rehabilitation Research and Training Centers, Field Initiated Projects, Advanced Rehabilitation Research Training Projects, and other NIDRR projects over the past 30 years. We have directly observed how these projects have contributed to improve health and participation outcomes for our patients, clients, and community partners and have increased capacity for research through our faculty and students who have benefited from participation in NIDRR funded projects. We strongly support NIDRR's unique role in funding applied rehabilitation and disability research. We do have some concern with the focus of the proposed Plan and the omission of technical assistance activities through direct services to consumers. As currently written, the Plan appears to diminish NIDRR's long-standing commitment to health and function and community participation research. Adequate health and function and community participation form the foundation on which successful employment of disabled persons is built. As stated in the call for comments, NIDRR has traditionally focused on the whole person in recognition that improvements in health and function and community living are critical antecedents to improved employment for individuals with disabilities. In truth, one cannot focus on any of these issues in isolation. While adequate health and function may be prerequisites for employment, failure to maintain adequate health and function is a frequent threat to maintenance of employment for disabled persons. Enhanced community participation creates social networks that facilitate acquisition and maintenance of employment. Employment, in turn, may result in improved health and participation for many persons. The wisdom of NIDRR's long-standing combined focus on these three aspects of life for persons with disabilities is seen when one tries to imagine how one could address the whole person without considering all three at once.

The proposed Plan does not acknowledge NIDRR's responsibilities to provide information, training and technical assistance on the Americans with Disabilities Act (ADA) and also provides no direction regarding:

1. how its technical assistance project (DBTAC-ADA Centers) will be managed
2. necessary resources will be allocated; and
3. activities will be coordinated with other federal efforts on ADA implementation.

NIDRR's omission in the Plan of technical assistance on the ADA is a major concern as we believe technical assistance is, and will continue to be, critical to implementation of the Americans with Disabilities Act. The ADA is complex legislation that is not easily understood by the general population. Provision of this technical assistance is especially critical at this juncture with the passage of the ADA Amendments Act and other major changes to ADA regulations.

The TIRR Research Council strongly urges NIDRR to revise the proposed Plan to restore balance in planned funding for research among the three areas of health and function, employment, and community participation and to restore technical assistance on the ADA as an area of focus. In view of the limited attention given to these issues by other federal agencies that fund rehabilitation research, it is crucial that NIDRR maintain its historical, special role in funding research and technical assistance to meet all the needs of persons with disabilities. In the end, a balanced focus of funding priorities across these funding areas will result in the best overall quality of life including employment for persons with disabilities. One cannot attain economic self-sufficiency, positive personal identity, and satisfaction in life without health and community participation regardless of one's employment status. One cannot maintain employment in the absence of health and community participation. Researchers and policy makers cannot understand how to promote employment of persons with disabilities without understanding how to promote health and function and community participation for persons with disabilities.

CONTRIBUTOR: Mark Sherer, Ph.D., ABPP/Cn
William H. Donovan, M.D.
Lex Frieden
Angelle Sander, P.D.
Daniel E. Graves, Ph.D.
Gerard E. Francisco, M.D.
Jerome S. Caroselli, Ph.D.
Allison N. Clark, Ph.D.
Lynne C. Davis, Ph.D.
Richard E. Petty, MBA
Bernard V. Silver, Ph.D.
Wendy Wilkinson, JD
TIRR Memorial Hermann
mark.sherer@memorialhermann.org
(713) 704-4000

DCN: 349

RECEIVED: 3/16/2009

COMMENT: The purpose of this letter is to provide comments to the Assistant Secretary for Special Education and Rehabilitative Services on behalf of the undersigned members of the Disability and Rehabilitation Research Coalition (DRRC) regarding the proposed long range plan (FYs 2010-2014) for the National Institute on Disability and Rehabilitation Research (NIDRR).

Since the U.S. Congress established The National Institute on Disability and Rehabilitation Research (NIDRR) in 1978, it has served as the flagship federal agency on disability and rehabilitation research. NIDRR is a mission-oriented agency-its mission is to explore the interaction of individual characteristics and environmental factors and their effects on the participation of individuals with disabilities in the home, community, school, and workplace. NIDRR carries out its mission by generating new knowledge through research and development, promoting its effective use (knowledge translation), and building the capacity of institutions and individuals to conduct high quality research and development.

In the two previous long-range plans covering FY1999 through the present, NIDRR has recognized that in order to carry out its mission, research and development activities must focus on three major life domains:

1. Employment,
2. Participation and community living; and
3. Health and function (including medical rehabilitation interventions to improve function and health status research to improve overall health and wellness of people with disabilities).

The proposed plan modifies this longstanding focus on the major life domains of employment, participation and community living, and health and function and instead specifies that the improvement of employment outcomes [will be] the focus of its long range plan for FYs 2010-2014. [74 FR at page 2566] Consistent with the focus on employment, the proposal only makes passing reference to health and function research and, when mentioned, health and function research is primarily mentioned in the context of employment and employment outcomes.

I believe that making employment the focus of research over the next 5 years is short-sighted and a departure from the mission of NIDRR. There needs to be a balance of research involving all three major life domains mentioned above. Without health and function, individuals with disabilities are less likely to participate in the community and employment. In the past NIDRR has appropriately recognized that there are many instances in which meaningful improvements in health and function may not always translate directly into changes in vocational outcomes. In addition, the focus on employment undermines NIDRR's mission to improve participation of persons with disabilities in the home, community, and school, as well as in the workplace.

People with disabilities of all ages, including the young and old as well as working age Americans with disabilities, must benefit from the research and development activities conducted by NIDRR. NIDRR must maintain a broad portfolio of disability and rehabilitation research that, in the words of the Rehabilitation Act, is designed to maximize the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities of all ages. In order to fully and faithfully carry out NIDRR's mission, I urge the new Assistant Secretary for Special Education and Rehabilitative Services and the Director of NIDRR to restore the broad focus of NIDRR's research and development activities to recognize the critical importance of all major life domains affecting persons with disabilities, i.e., participation and community living, health and function, as well as employment.

CONTRIBUTOR: Ralph J. Marino, M.D., MS, FACRM
Jefferson Medical College of Thomas Jefferson University
ralph.marino@jefferson.edu
(215) 955-5756

DCN: 350

RECEIVED: 3/16/2009

COMMENT: The purpose of this letter is to provide comments to the Assistant Secretary for Special Education and Rehabilitative Services on behalf of the undersigned members of the Disability and Rehabilitation Research Coalition (DRRC) regarding the proposed long range plan (FYs 2010-2014) for the National Institute on Disability and Rehabilitation Research (NIDRR).

Set out below is a summary of our comments followed by a more in depth recitation of our position. The in depth recitation includes a brief review of the historical and policy context of NIDRR, a statement of principles that guided our review of the proposal, and our recommendations regarding the LRP mission statement, the inclusion of a logic model, goals, outcomes, focus, operational performance measures, and research agenda.

SUMMARY OF COMMENTS

Since the U.S. Congress established The National Institute on Disability and Rehabilitation Research (NIDRR) in 1978, it has served as the flagship federal agency on disability and rehabilitation research. NIDRR is a mission-oriented agency—its mission is to explore the interaction of individual characteristics and environmental factors and their effects on the participation of individuals with disabilities of all ages in the home, community, school, and workplace. NIDRR carries out its mission by generating new knowledge through research and development, promoting its effective use (knowledge translation), and building the capacity of institutions and individuals to conduct high quality research and development.

In the two previous long-range plans covering FY1999 through the present, NIDRR has recognized that in order to carry out its mission, research and development activities must focus on three major life domains:

- Employment,
- Participation and community living; and
- Health and function (including medical rehabilitation interventions to improve function and health status research to improve overall health and wellness of people with disabilities).

In addition, NIDRR has recognized the need to focus on technology for access and function and disability demographics.

On January 15, 2009, five days before the inauguration of President Obama, the acting Assistant Secretary for Special Education and Rehabilitative Services published a notice in the Federal Register proposing a long range plan for NIDRR for Fiscal Years 2010-2014. The proposed plan modifies this longstanding focus on the major life domains of employment, participation and community living, and health and function and instead specifies that the improvement of employment outcomes [will be] the focus of its long range plan for FYs 2010-2014. [74 FR at page 2566] Thus, the focus of research and development activities relating to the life domains of participation and community living and health and function have been relegated to a less prominent status under the proposal, thereby undermining NIDRR's mission to improve participation of persons with disabilities of all ages in the home, community, school, as well as the workplace.

Consistent with the focus on employment, the proposal only makes passing reference to health and function research and, when mentioned, health and function research is primarily mentioned in the context of employment and employment outcomes. For example, the Notice describes the purpose of health and function research as critical antecedents to improved employment for individuals with disabilities. Under research and development the proposed long-range plan articulates the following goal advance knowledge related to disability and rehabilitation through research and development, with particular emphasis on improving employment and participation outcomes for individuals with disabilities. Objective 1.1 focuses on increasing knowledge of the factors that serve as facilitators or barriers to improved employment outcomes Objective 1.2 focuses on increasing knowledge of the health and function factors that serve as facilitators of or barriers to improved employment and participation outcomes. [74 FR at pages 2566-2567]

As stated above, the references to non-employment related research; including health and function research is made almost reluctantly; NIDRR proposes to use the goals, objectives and strategies described in the following section to guide the development of grant priorities in the coming years. Focusing the Plan on employment and employment outcomes will not prevent NIDRR from continuing the work it is currently funding. NIDRR will maintain a broad array of mandated programs it currently supports (e.g., the rehabilitation engineering research centers and spinal cord injury model systems program) and, where

possible, will establish a link between each new priority it funds through these programs and employment outcomes.

We believe that there is a continuing need for NIDRR to recognize and focus on health and function as a distinct life domain. Without health and function, individuals with disabilities are less likely to participate in the community and employment. In the past NIDRR has appropriately recognized that there are many instances in which meaningful improvements in health and function may not always translate directly into changes in vocational outcomes. We also believe that there is a continuing need for NIDRR to recognize and focus on participation and community living as a distinct life domain.

So there is no misunderstanding about the position of the undersigned organizations regarding the appropriate focus of NIDRR's research and development activities, we want to make it perfectly clear that we also fully support research and development activities that focus on employment. It is critical for NIDRR to advance employment-related innovations (both demand and supply side), improve delivery of services at the systems level (with particular emphasis on improving the effectiveness of services authorized under the Rehabilitation Act), and advance public policy that makes work pay (work incentives and the seamless delivery of services and supports). What we are saying is that if NIDRR is to accomplish its congressionally-mandated mission, it must continue the longstanding policy of focusing its research and development activities on all major life domains, including participation and community living, health and function, as well as employment.

Infants, children, adolescents, and the elderly, as well as working age Americans with disabilities must benefit from the research and development activities conducted by NIDRR. NIDRR should reaffirm its longstanding recognition that rehabilitation is not limited to short-term engagement for those individuals experiencing injuries or illnesses, but also includes ongoing management of chronic conditions as people move through their lives. NIDRR must maintain a broad portfolio of disability and rehabilitation research that, in the words of the Rehabilitation Act, is designed to maximize the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities of all ages.

In order to fully and faithfully carry out NIDRR's mission, we urge the new Assistant Secretary for Special Education and Rehabilitative Services and the Director of NIDRR to restore the broad focus of NIDRR's research and development activities by recognizing the critical importance of all major life domains affecting persons with disabilities, i.e., participation and community living, health and function, as well as employment.

IN DEPTH RECITATION OF COMMENTS

HISTORICAL AND POLICY CONTEXT

Historically, Congress established NIDRR to serve as the Nation's lead federal agency on rehabilitation and disability research and, as such, to maintain a broad portfolio of research designed to maximize the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities of all ages. [See, Section 200 of the Rehabilitation Act of 1973, as amended] Since 1978 and in the two most recent long-range plans, NIDRR has recognized that its mission is to generate new knowledge and promote its effective use to improve the abilities of people with disabilities to perform activities of their choice in the community, and also to expand society's capacity to provide full opportunities and accommodations for its citizens with disabilities.

NIDRR also has recognized the substantive focus of its investment in Research and Development related to maximizing the participation of people with disabilities. More specifically, research and development activities are centered on the three major life domains of interest to NIDRR:

- Employment;
- Participation and community living; and
- Health and function.

[See, 71 Federal Register at page 8173] The U.S. Department of Education's Strategic Plan for Fiscal Years 2007-12 reaffirms the Department's obligations to fulfill its congressional mandate to continue to support and monitor research leading to the development of interventions that support health and physical function, participation and integration into the community, and employment of individuals with disabilities. [See, Page 31, emphasis added]

In sum, Congress directed NIDRR to serve as the lead and primary agency to conduct disability and rehabilitation research related to employment and participation and integration into the community. Congress

also directed NIDRR to serve as the lead and primary agency supporting medical rehabilitation research that enhances the health and function of people with disabilities i.e., research designed to enhance treatments that allow persons with traumatic brain injury, spinal cord injury, and other impairments to more fully participate in activities of daily living and be part of society. If we are to achieve the promises of the Americans with Disabilities Act, Congress expects NIDRR to lead the way in learning about new and better strategies to the improve community integration, health and function as well as the employment of people with disabilities.

Consistent with Congressional intent, NIDRR historically has recognized that there are many instances in which meaningful improvements in participation and community integration may not always translate directly into vocational outcomes, especially for infants, children and adolescents and older Americans who are not working. NIDRR also has recognized that there are many instances in which meaningful improvements in health and function may, but do not always translate directly into changes in vocational outcomes. The continuing need for medical rehabilitation research is to improve function and the need for health status research is to improve overall health and wellness of persons with disabilities. Without health and function, individuals with disabilities are less likely to participate in the community and in employment. Indeed, good health and function are essential to the achievement of these other very important goals.

Based on our understanding of congressional intent, as reflected in our review of NIDRR's historical and policy context, we have developed a set of principles to help guide the development of our comments regarding the content of NIDRR's new LRP.

NIDRR's new LRP should:

- Reflect NIDRR's history and policy designating NIDRR as the lead federal agency on rehabilitation and disability research and NIDRR's need to maintain a broad portfolio of research;
- Embrace the breadth and depth of critical domains impacting the lives of persons with disabilities (employment, participation and community living, and health and function);
- Address the needs of persons with disabilities of all ages, including infants, children, adolescents, older Americans as well as individuals of working-age;
- Recognize that rehabilitation is not only an intervention designed to fix someone who has been injured but includes ongoing management of chronic conditions;
- Build on NIDRR's current LRP;
- Include a Logic Model to help select those research activities to be supported that are most likely to lead to intermediate and long-term outcomes of interest;
- Build on the strong history of research accomplishments in all critical life domains; and
- Insist on the use of management strategies, including high-quality peer review, that result in support of rigorous research that is of utility to stakeholders.

MISSION

Consistent with Title II of the Rehabilitation Act, we recommend that NIDRR's new LRP include the following mission statement:

The mission is to generate new knowledge and promote its effective use to improve the abilities of people with disabilities of all ages to perform activities of their choice in the home, community, school, and workplace and also to expand society's capacity to provide full opportunities and accommodations for its citizens with disabilities.

LOGIC MODEL

We recommend that NIDRR's new LRP recognize that significant gaps exist in knowledge, skills, policy, practice, and system capacity that prevent people with disabilities from having equal access to opportunities for employment, participation and community living, and health and function. The substantive focus of NIDRR's investment activity should be centered on the three major life domains of interest to NIDRR-employment, participation and community living, and health and function. In addition, the Logic Model should include two additional domains-technology for access and function and disability demographics.

With respect to employment, for many people with disabilities, employment that is challenging, fulfilling, and adequately compensated is the ultimate rehabilitation outcome. Employment shapes the lives of individuals with disabilities who are interested in and qualified for workforce participation. At the individual and systems level success should be measured in terms of acquisition, improvement, and enhancement of skills,

productivity, earnings, job retention and advancement, and benefits. NIDRR should advance employment-related innovations that contribute to success at work and subsequent improvements in quality of life in education, home, and community. Research supported by NIDRR must continue to focus on improving the implementation of employment-related activities supported by OSERS, including the Rehabilitation Services Administration (RSA).

With respect to participation and community living, NIDRR should focus on the extent to which people with disabilities are participating in the community in a manner that is meaningful to them and support research into programs and services that expand the scope of participation of people with disabilities, especially those with the most severe disabilities. NIDRR should sponsor research to improve knowledge of individual and societal level factors that may serve as barriers to, or facilitators of, participation among all people with disabilities. Research may include evaluation of specific participation-promoting programs, interventions and products, as well as development of methods, measures, and theories to enhance scientific rigor of these evaluations.

With respect to health and function, research on maximizing health and function among people with disabilities is critical to the achievement of NIDRR's mission and the associated higher-order goals of employment and community participation. Functional ability reflects the complex interaction between individuals and the environments in which they live. In conceptualizing health and function research to improve the lives of individuals with disabilities, NIDRR should posit a growing need for research on medical rehabilitation interventions to improve function and for health status research to improve overall health and wellness of people with disabilities.

GOALS

The LRP should identify strategic goals that communicate NIDRR's main themes and directions. The goals should reflect NIDRR's mission and align with the targeted outcomes arenas depicted in the Logic Model. We recommend that NIDRR's new LRP include the following four goals:

- Research and Development (R & D)-Advance knowledge about disability and rehabilitation through research and development.
- Knowledge Translation (KT)-Increase the use of research and development knowledge to improve policy, practice, behavior and systems related to disability and rehabilitation.
- Capacity Building (C-B)-Increase the capacity of individuals (particularly those with disabilities) and institutions to conduct high-quality disability and rehabilitation research and development.
- Management-continuously improve NIDRR outcomes through effective management, monitoring and use of program data.

OUTCOMES

Long-term outcomes arenas. NIDRR's long-term outcomes should focus on eliminating disparities between people with and without disabilities in employment, participation and community living, and health and function. These long-term outcomes should serve as critical anchor points guiding all strategic planning and research management efforts.

Short-term outcomes arenas. Within the logic model, there should be four short-term outcome arenas corresponding to NIDRR's investments in four functional arenas. These functional arenas are R&D, KT, C-B, and management corresponding to NIDRR's four strategic goals. R&D should be further divided to reflect three stages of knowledge development-

1. discoveries;
2. new or improved theories, measures, or methods; or
3. interventions, products, devices, and environmental adaptations.

FOCUS

At the heart of NIDRR's mission should be the support of research to improve the lives of people with disabilities. We recommend that NIDRR's new LRP focus attention on the major life domains as set out in the Logic Model. Improving employment outcomes should be a major concern of NIDRR as should improving the functioning of OSERS' programs related to employment, including vocational rehabilitation and programs related to the education of transition-age youth with disabilities. Similarly, improving participation and community living outcomes (including maximizing choices for persons with disabilities as they select their dwellings, transportation, and life activities) should be a major concern of NIDRR. Furthermore, improving health and function outcomes should be a major focus of NIDRR research as advances in this domain are

the foundation for attaining outcomes related to employment and participation and community living.

OPERATIONAL PERFORMANCE MEASURES

The future research agenda for NIDRR should rest on the long-term outcomes depicted in the Logic Model, which call for the elimination of disparities in employment, increasing participation and community living, and improving health and function for people with disabilities and the general population. However, because achieving this desired end-result requires changes in the overall condition of people with disabilities that go beyond the reach of the Institute's mission, it is necessary to articulate an additional set of more operational performance measures with respect to employment, participation and community living, and health and function.

RESEARCH AGENDA

The research agenda, as we suggested, must reflect the three critical life domains of individuals with disabilities-employment, participation and community living, and health and function. The proposed LRP focuses on the research agenda related to the employment domain. Set out below are our comments regarding the participation and community living and health and function domains.

NIDRR's research agenda in the domain of participation and community living should be designed to strengthen the scientific basis of policies and practices aimed at enhancing participation among people with disabilities by providing information and analyses that improve understanding of participation levels among individuals with disabilities and the multiple barriers and facilitators of their participation. NIDRR's research agenda should also strengthen participation-related research and practice by increasing the availability of validated theories, measures, and methods. These theories, measures, and methods should improve data sources and estimates, and should enable better identification, evaluation, and prediction of the factors that facilitate or impede participation and community living. These improvements should enhance the credibility of research and thus increase the utilization of research findings.

As stated above, maximizing health and function of people with disabilities is critical to the achievement of community participation and employment. Functional ability reflects the complex interaction between individuals and the environment in which they live. Accordingly, NIDRR should conceptualize and examine issues of health and function at both the individual and systems levels.

Specifically, the health and function agenda at the individual level should fund research that supports the development and evaluation of new interventions, products, devices, and environmental adaptations aimed at improving the health status and functional abilities of people with a wide range of disabling conditions. These interventions should address the needs of people who are aging with disability, with particular emphasis on minimizing secondary health conditions and disabilities. These interventions should also address the unique needs of infants, children and adolescents with disabilities. NIDRR should also fund research that leads to the development of the next generation of valid and reliable measures of health and functional status among people with disabilities.

At the systems level, NIDRR-supported research should focus on the structure, organization, and delivery of health care and medical rehabilitation services. Also at the systems level, NIDRR should study access to health care and rehabilitative services, and the complex delivery systems used for those services. Individual level research should focus on the development and testing of new interventions that improve functional and health outcomes for individuals. As already stated, in conceptualizing health and function research to improve the lives of individuals with disabilities, NIDRR should posit a growing need for research on medical rehabilitation interventions to improve function and for health status research to improve overall health and wellness of people with disabilities.

At the systems level, NIDRR should also fund research that will generate new knowledge about the systematic causes and consequences of substandard access to rehabilitation, healthcare, and mental health care services for people with a wide range of disabling conditions. This research will identify and evaluate the effectiveness of specific service delivery approaches and payment models aimed at minimizing physical, social, and economic barriers to the full spectrum of health, mental health, and rehabilitation services that are needed by people with disabilities. In addition, research is needed to support the development of evidenced-based practice methods that are consistent with rehabilitation treatment practices that currently exist in the field and with the rehabilitation research methods used to develop new assessments and interventions.

Overall Agenda-NIDRR's research agenda in the area of health and function should be designed to increase the number of validated new or improved methods for assessing function and health status; increase the number of interventions, products, and devices demonstrated to be efficacious in improving health and

function outcomes in targeted disability populations; and increase understanding of the underlying structures and processes that facilitate or impede equitable access to rehabilitation and physical and mental healthcare by people with disabilities.

Thank you for this opportunity to submit comments to NIDRR's next Long Range Plan.

Sincerely,

American Academy for Physical Medicine and Rehabilitation

American Academy of Orthotists and Prosthetists

American Association of People with Disabilities

American Association of Spinal Cord Injury Psychologists and Social Workers

American Congress of Rehabilitation Medicine

American Medical Rehabilitation Providers Association

American Occupational Therapy Association

American Physical Therapy Association

American Therapeutic Recreation Association

Amputee Coalition of America

ARA Institute

Association of Academic Physiatrists

Association of Rehabilitation Nurses

Brain Injury Association of America

Christopher and Dana Reeve Foundation

National Association for the Advancement of Orthotics and Prosthetics

National Association of Rehabilitation Research Training Centers

National Association of State Head Injury Administrators

National Council on Independent Living

National Multiple Sclerosis Society

National Spinal Cord Injury Association

Paralyzed Veterans of America

United Spinal Association

CONTRIBUTOR: Robert "Bobby" Silverstein
Disability and Rehabilitation Research Coalition
bobby.silverstein@ppsv.com
(202) 872-6754

DCN: 351

RECEIVED: 3/16/2009

COMMENT: I have read the recent proposed changes to the NIDRR long-range plan outlined in the Federal Register. I, like many others in the field of medical rehabilitation, am concerned about the apparent shift in focus away from health and function research and what appears to be a single focus on employment research as a funding priority for future NIDRR grants. As a former model systems principal investigator for NIDRR, I know what a tremendous difference the NIDRR funding in medical rehabilitation systems of care can make in the well-being of a community. I hope that you will reconsider this change in focus and revert to a more balanced view for future funding priorities. Thank you for your consideration.

CONTRIBUTOR: Steve M Gnatz, M.D., MHA
Loyola University Medical Center
sgnatz@lumc.edu
(708) 216-4994

DCN: 352

RECEIVED: 3/16/2009

COMMENT: NIDRR's Proposed Long Range Plan materially departs from previous plans by focusing on a single category of research *employment* rather than on all three important areas of research. NIDRR's mandated mission is relegated to mere mention within an employment context.

Health and function, employment, and community participation are all essential components of comprehensive rehabilitation.

Please reconsider your plan to include all three aspects.

CONTRIBUTOR: Alberto Esquenazi, M.D.
MossRehab
aesquena@einstein.edu
(215) 663-6676

DCN: 353

RECEIVED: 3/16/2009

COMMENT: On behalf of the Brain Injury Association of Maryland (BIAM) and the 1.4 million Americans who sustain a traumatic brain injury (TBI) each year, I am writing to express my deep concern regarding the proposed long range plan (FYs 2010-2014) for the National Institute on Disability and Rehabilitation Research (NIDRR). As proposed, NIDRR's plan will all but abandon the agency's longstanding commitment to research in the life domains of health and function as well as participation and community living, and instead, narrowly focus on employment. In general, BIAA believes such an approach would undermine NIDRR's mission to improve participation of persons with disabilities of all ages in varied settings. Specifically, BIAA believes the proposed approach would have long-lasting, detrimental effects on individuals with brain injury.

For people with brain injury, health and function research (including medical rehabilitation interventions) is more than an antecedent to employment. Indeed, the knowledge stemming from the health and function portion of NIDRR's research portfolio is vital to maintaining the overall health and wellness of individuals with brain injury and to maximizing their independence. Moreover, while such interventions do not always translate directly into changes in vocational outcomes, they do reduce dependency on public health and welfare systems and contribute significantly to the body of knowledge on TBI.

For example, the NIDRR's TBI Model Systems are the only source of non-proprietary longitudinal data on what happens to people with brain injury immediately after the injury and throughout their lifetimes. The Model Systems are a key source of evidence-based medicine, and serve as a proving ground for future researchers. TBI Model Systems researchers are currently working closely with the Department of Veterans Affairs to improve the treatment of returning service members with brain injuries.

Brain injury is not an event or an outcome. It is the beginning of a lifelong disease process.

NIDRR should reaffirm its longstanding recognition that rehabilitation is not limited to short-term engagement for those individuals experiencing injuries or illnesses, but also includes ongoing management of chronic conditions as people move through their lives. NIDRR must maintain a broad portfolio of disability and rehabilitation research, including TBI-related Rehabilitation Research and Training Centers (RRTC's) and field-initiated investigations, which make similar contributions to ensuring the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with TBI, regardless of age.

In order to fully and faithfully carry out NIDRR's mission, the Brain Injury Association of Maryland strongly urges the new Assistant Secretary for Special Education and Rehabilitative Services and the Director of NIDRR to restore the broad focus of NIDRR's research and development activities by recognizing the critical importance of all major life domains affecting persons with disabilities, i.e., participation and community living, health and function, as well as employment.

CONTRIBUTOR: Diane D. Triplett
Brain Injury Association of Maryland
volunteer5@biamd.org

DCN: 354

RECEIVED: 3/16/2009

COMMENT: I would like to make the following comments regarding the proposed long-range plan:

1. A wholesale shift of almost all of NIDRR's research and capacity building to employment and employment-related activities is proposed. This is justified by a pressing need for additional research to improve access to appropriate employment, retention of employment, and career advancement for individuals with disabilities. However, no further justification is provided, let alone evidence. The following paragraphs offer a reference to the aging of the US population, and the claim that this will be accompanied by an increase in the number of individuals with disabilities because individuals 45 and older experience a higher rate of disabilities than do younger individuals. ... Many of these individuals will continue to work past the age of 65. However, many will not, as onset of disability traditionally has been taken as a reason (or excuse) to take early retirement by those over 50-55. More to the point, the compression of morbidity hypothesis (Fries et al.) which is well-supported suggests that morbidity and disability resulting from chronic diseases increasingly will be compressed into those ages (70+, 80+) during which employment typically is a point in the past.

A second paragraph in which the need for employment-related research is argued holds that The characteristics of individuals with disabilities seeking assistance to perform major life activities are changing as well. Many veterans of ongoing conflicts between the United States and other countries are returning with disabilities. approximately 40 percent of returning veterans sustained mild traumatic brain injury or post-traumatic stress disorder. Enabling these veterans to reenter the workforce has become an important issue for them and for the United States. This is not a change in disability type or severity. Traumatic brain injury, combined with PTSD or by itself, has been recognized by the rehabilitation field and the Federal Government as a significant public health issue of young Americans since the 1970s. There is indeed a need to help returning veterans with TBI to return to employment, but it is not clear that employment research is to be the focus of research. Cognitive rehabilitation and other traditional interventions, which prepare veterans with TBI as well as civilians with TBI for home, community as well as employment functioning may have a better payoff.

In addition, nowhere in this proposed Plan is there any mention of the need and potential of collaboration with the Department of Defense or the Department of Veterans administration to address these issues. Congress in recent years has made large amounts of research funding available to study health and functioning issues of returning veterans, and these agencies have, probably for the first time ever, sought out advice from and collaboration with NIDRR and its funded researchers. The Plan might in its Management Strategy lay out how this collaboration might be exploited to benefit veterans and civilians, potential workers or not, but this section of the Plan is limited to a description of what NIDRR is currently doing to manage its portfolio.

Even if one were to grant that employment research deserves a larger or much larger emphasis in the Plan, this should not come at the cost of complete disregard of anyone who is not of employment age or potential. The words child or adolescent do not occur anywhere in this document. Adolescents are mentioned only indirectly in a sentence on research to enhance the transition of students to postsecondary education and employment. The words elderly or aged do not occur either; the elderly are only mentioned indirectly in the paragraph mentioning the aging of the population. This constitutes a serious disregard of the phases of life that bracket the phase of employment. The whole tenor of the document takes us back to an earlier age during which the assumption was that one lives to work, rather than today's zeitgeist expressing that one works to live.

2. The recently published report *The future of disability in America* (Field, M., & Jette, A.M. (Eds.), Washington, DC: The National Academies Press, 2007)

CONTRIBUTOR: Marcel P.J.M. Dijkers Ph.D. FACRM
Mount Sinai School of Medicine
marcel.dijkers@mountsinai.org
(212) 659-8587

DCN: 355

RECEIVED: 3/16/2009

COMMENT: I am writing to object to the shift in focus that makes employment the primary focus instead of having employment continue as 1 of the 3 areas of focus.

On May 19, 1999, I fell off a ladder and sustained a Traumatic Brain Injury (TBI). I attempted to return to work but was not able to continue to work because of the problems caused by my TBI. I was 57 years old when I sustained my TBI. The primary residual effects that keep me from working are:

1. Fatigue;
2. Lack of cognitive stamina and endurance;
3. Slower abilities to process and integrate information;
4. Physical pain.

I have not been able to return to "paid employment" because of the continuing limitations from my TBI; however, I have been able to engage in meaningful volunteer activities that enable me to contribute to our community and our region. Before my TBI, I was a psychiatrist. Now, I am "working" to educate others about TBI and to advocate for both the persons with a TBI and for their families. My stories are outlined in the attachments.

I hope that you will reconsider your present plans to narrow the focus for the next funding cycle. Many of want to return to paid employment but we are not able to do so because of our limitations. But, with the help of others we can find ways to reengage in our communities and find meaning in our lives.

Thank you for your consideration.

CONTRIBUTOR: Tom Tatlock, M.D.
tatlock.tom@gmail.com

DCN: 356

RECEIVED: 3/16/2009

COMMENT: I am writing to express my grave concern about the proposed NIDRR Long-Range Plan that was published in the Federal Register (Jan. 15, 2009). The Plan, as written, as significantly diverged from the 3 major areas of research on which NIDRR has traditionally focused. Indeed, the 3 areas span the continuum of care and concern for individuals with disabilities: health and function; community participation; and employment. However, with the elimination of health and function research and community participation research from the NIDRR research portfolio (except as they support individuals with disabilities returning and staying in employment), NIDRR is dangerously close to eliminating research initiatives and outcomes that can immediately and directly impact the lives of individuals with disabilities.

While it is acknowledged that employment rates are very low in individuals with disabilities, it is not appropriate to assume that ALL individuals with disabilities have employment as their primary concern. Indeed, one of the lessons that we have learned over the years is that individuals with disabilities must be given a voice in directing the areas in which research should be focused. Health problems, aging with disabilities, barriers and facilitators to accessing the community, assistive technology, and improving acute and long-term global outcomes for individuals with disabilities are issues that almost everyone with a disability will encounter at some time post-injury/diagnosis, while return to employment may be appropriate for a smaller percentage of individuals with disability due to the nature of the disability and/or age, as well as other factors.

Therefore, NIDRR would be wise to seriously re-consider the current proposed Long-Range Plan and return to the 3-pronged research mandate in which it has proven so successful; that is, supporting research in Health and Function, Community Participation/Integration, and Employment.

CONTRIBUTOR: Tamara Bushnik, Ph.D.
Santa Clara Valley Medical Center
tamara@tbi-sci.org
(408) 793-6446

DCN: 357

RECEIVED: 3/16/2009

COMMENT: The proposed Long Range Plan of NIDRR inappropriately limits research to the employment area. The research agenda must reflect the three critical life domains of individuals with disabilities—employment, participation and community living, and health and function. It is important that persons with disabilities be recognized and welcomed as participants in all phases of community life.

CONTRIBUTOR: William S. Pease, M.D.
Ohio State University Medical Center
william.pease@osumc.edu
(614) 293-3433

DCN: 358

RECEIVED: 3/16/2009

COMMENT: I am writing to you today to voice my serious concerns about the NIDRR Long Range Plan that was published in the Federal Register (Jan. 15, 2009).

The plan mentions NIDRR's unique role established by Congress to foster disability and rehabilitation research designed to enhance self-determination and participation in the HOME, COMMUNITY, and WORKPLACE. Historically, NIDRR has focused on 3 broad areas of research: health and function research, employment-related research, and research related to community participation. Contrary to congressional intent and longstanding policy and practice, the proposed Long-Range Plan departs significantly by focusing on one category of research (employment) rather than all 3 areas of research.

While employment is an important goal, it is not necessarily the primary goal for all individuals with disabilities. Research into health and function and community integration are also important goals (perhaps even more important, for without health and function and community integration there will be no employment). I think it is important that our participants have a voice in what sort of focus and projects NIDRR take on. That is our practice at our center, when deciding our research agenda: we talk to the people it will involve.

You currently have a research portfolio which involves the collaboration of many institutions (many of them Rehabilitation facilities). The model systems programs have been a rich source for increasing understanding of disability and what happens after disability. Most of the centers are not "employment specialists", for many acute rehabilitation centers, employment happens sometime post-discharge (frequently a year or more post hospitalization). Many of the local projects currently funded are clinical trials, a response to NIDRR's request for more research rigor. Very few have employment as the primary focus. Most are working in the areas of health and function or community integration. It would be a shame to lose the collaboration of so many centers, after working so many years to build it up. There is a big difference between making an area of research a priority and requiring that it be your major emphasis.

I think that you should seriously re-consider the current proposed Long-Range Plan and return to the 3-pronged research agenda which has proven to be successful; that is, supporting research in Health and Function, Community Participation/Integration, and Employment.

CONTRIBUTOR: Jerry Wright
Santa Clara Valley Medical Center
jerry.wright@hhs.sccgov.org
(408) 793-6430

DCN: 359

RECEIVED: 3/16/2009

COMMENT: I am writing to you on behalf of our department and the people with disabilities of all ages that we serve to ask that NIDRR withdraw the proposed Long Range Plan (LRP) for 2010–2014 and to revise the LRP to be consistent with Congressional Intent and the testimony provided during the hearings conducted last spring. In particular, my request represents the consensus of senior NIDRR investigators in our department including Drs. Kathleen Bell, Charles Bombardier, Mark Jensen, Kurt Johnson, George Kraft, Kathe Matrone, Sureyya Dikmen, Kathryn Yorkston, and myself.

The proposed Long Range Plan is narrowly focused on employment. While employment is a highly valued outcome for people with disabilities, employment outcomes are not feasible for many people with disabilities (e.g. see the testimony for the NIDRR hearings from family members of individuals with severe brain injuries), and are not appropriate for children. In addition, employment is only possible for people with disabilities in the context of a holistic approach focusing on health and function, accessible environments, information technology, and disability policy. The proposed LRP does address potential activities related to participation in general, but it does not explicitly validate the importance of a broader NIDRR agenda.

We recommend that NIDRR revise the long range plan to make it consistent with the NIDRR Mission Statement, to generate new knowledge and promote its effective use to improve the abilities of people with disabilities to perform activities of their choice and also to expand society's capacity to provide full opportunities and accommodations for its citizens with disabilities. In fact, the current LRP with the focus on Employment, Participation in Community Living, and Health and Function within the context of Technology and Demographics, is an excellent model.

We also encourage NIDRR to validate in the plan the importance of legal and policy advocacy, and civil rights to increase opportunities for full participation by people with disabilities. The Disability and Business Technical Assistance Center (DBTAC) Program as well as other NIDRR entities represent a significant and valuable proportion of the NIDRR portfolio.

CONTRIBUTOR: Peter C. Esselman, M.D.
University of Washington
esselman@u.washington.edu
(206) 744-3167

DCN: 360

RECEIVED: 3/16/2009

COMMENT: I send this email to provide comment on NIDRR's long-range plan 2010-2014. I am a long-time follower of NIDRR's funding pattern and affiliate of NIDRR beginning with an RRTC post-doctoral fellowship, a grant funding applicant, and a grant and program reviewer.

I appreciate the effort and work NIDRR has put into developing the 2010-2014 plan. And I recognize the advancements NIDRR has made over the past decade in moving towards strong science by promoting the use of tools like logic models by its grantees.

However, I have strong reservations about the 2010-2014 plan related to its ability to lead and advance the field of disability and rehabilitation research. I will list my reservations below:

1. While I applaud the effort of NIDRR to directly address the issue of employment among persons with disabilities, I am concerned with the approach. Employment research aims in the current plan, almost exclusively targets the capability of the individual to become "employable". While most certainly the development of capabilities for employment are critical for people with disabilities - and often people with disabilities are marginalized in educational, human and social capital building programs - employment discrimination remains a central problem for people with disabilities seeking work. If NIDRR is going to directly target employment, it must also directly target the social and employment environments that set expectations, put work policies in place, etc. that act as barriers to employment. If NIDRR does not include this balance in its research aims, for all practical purposes, it ignores the social model of disability as its fullest operationalization and will only obtain a partial (at best) advancement in employment for people with disabilities.

2. Given the radical advancement in lifespan of people with disabilities, NIDRR should ensure that its research foci build a knowledge base that relates to the life course of disability. What is the difference between living long-term or short-term with disability?

We don't know scientifically much about this and certainly are unable to inform the development of evidence-based policies that would help promoted independence, self-determination, and participation over the life course. This demographic shift is global, it is permanent.

NIDRR should lead in this area as large social welfare policies in the United States including SSI, SSDI, OASI, Medicaid, Medicare, food stamps, housing, transportation, Older Americans Act (this list can go on) need to be informed by this demographic shift. This shift has a direct relationship to both employment and poverty over the life course for people with disabilities as well as health disparity. Modifications will likely be made in these policies without scientific input if none is available. NIDRR should advance this work and develop the research voice in this area by infusing aging-related or life-course related issues throughout its research directives.

3. The NIDRR long range plan does not adequately reflect what is now universally recognized as a critical national issue - racial/ethnic health, income, and social welfare disparities in the United States. As the leading national funder of disability and rehabilitation research, NIDRR must join NIH and other federal agencies to explicitly mandate that its grantees be inclusive of minority populations in the research itself and in research dissemination and translation efforts.

NIDRR grant scoring criteria give little weight to this issue and NIDRR grant calls do not mandate attention to minority populations. It is beyond time for NIDRR to move this agenda forward.

4. Poverty. NIDRR has rarely explicitly promoted research that investigated income and assets among people with disabilities. However, it is well established that nearly all negative outcomes related to independent living, participation, health care, social engagement, rehabilitation, employment (etc.) issues for people with disabilities are more entrenched among low-income and poor people with disabilities. NIDRR has recently taken an interest in asset development for people with disabilities, which is forward movement in this area. However a modest interest in asset building and tax policy is not enough. Poverty research is a strongly established field. NIDRR should increasingly invest in poverty reduction research for people with disabilities but it also must demand a high level of scientific rigor in this work that will capture attention in this field. NIDRR should work to bring poverty-researchers into its applicant pool and encourage disability researchers to widen their expertise to include issues of poverty reduction.

5. Scientific rigor. NIDRR has for too long had very minimal criteria for scientific rigor in its grant

applications. Additionally, in most review processes, the points awarded for the scientific merit of a research project are many fewer than are awarded for the administration of the project. This is unacceptable at this stage in science. Too many awards are granted based on organizational capacity with the result that only modest scientific work is produced for arguably large sums of money. NIDRR should not be in the business of funding "research shops" but in the business of funding high quality science. Operational capacity should be considered in the review process, but should be worth a small percentage of points.

Additionally, review criteria need substantial revision in their definition and operationalization as reviewers have virtually no guidance on how to score applications, thus scoring across reviewers can range as much to 50 points on a 100 point application. The lack of a strong review process and scientifically rigorous reviews is a disincentive for top-quality researchers to apply for NIDRR funding. Further, NIDRR must begin to include past performance of a grantee in its review criteria. The current system permits prior grantees who are excellent application writers but poor or mediocre research performers to continue to obtain additional funding. When this occurs (which is not unusual), NIDRR is arguably not leading scientific and knowledge development but merely serves as a funding source.

In closing, I strongly encourage NIDRR to make revisions in its long-range plan to address the issues I mention above. NIDRR has the potential to lead disability and rehabilitation research in the United States. It must, however, move beyond the narrowness proposed in the plan to more comprehensively and rigorously approach scientific research that improves the lives of people with disabilities as individuals and as a population group.

CONTRIBUTOR: Michelle Putnam, Ph.D.
Simmons College
michelle.putnam@simmons.edu
(617) 521-3956

DCN: 361

RECEIVED: 3/16/2009

COMMENT: I am writing in response to the National Institute on Disability and Rehabilitation Research (NIDRR) Notice of Proposed Long-Range Plan for Fiscal Years 2010-2014.¹ I am a physician, a researcher, and a person with a disability (C6/7 tetraplegia since 1992). I believe the proposed 2010-2014 Plan focuses primarily on one research domain, employment, represents a significant negative shift from NIDRR's 2005-2009 Long Range Plan,² which placed equal emphasis on five research domains: employment; health and function; participation and community living; technology; and disability demographics. I believe that NIDRR's shifting of its research focus to emphasize primarily employment overlooks the impact and diminishes the role the other research domains, particularly health and function, have on achieving and maintaining employment in individuals with disabilities.

One of NIDRR's great strengths has been its holistic approach to individuals with disabilities. Importantly, improvements in health and function, technology, and community participation are all critical antecedents to employment. The very example provided by NIDRR in the Notice illustrates this point: a manual wheelchair user must be able to maintain good arm function to maintain mobility that may be needed for employment. Improving arm function and mobility will also assist the individual in other areas as well, including independent living and community participation. ¹(p.2566) Much of what is known about the impact of upper limb overuse in manual wheelchair users comes from prior research from the NIDRR-funded Spinal Cord Injury Model System Centers. The Consortium guidelines on the Preservation of Upper Limb Function Following Spinal Cord Injury³ are an output from Dr. Michael Boninger and his NIDRR-funded collaborative project in SCI research,⁴ the Collaboration on Upper Limb Pain in Spinal Cord Injury (CULP-SCI). This very example illustrates the importance of all domains in rehabilitation research.

It is imperative that NIDRR continue to follow the pathway it has built over the last 3 decades. Importantly, the 2005'09 Long Range Plan continued NIDRR research efforts developed under the 1999-2003 Long-Range Plan by continuing to emphasize the major research domains of employment, participation and community living, health and function, and technology, while elevating the area of disability demographics to a major domain to reflect and reinforce the importance of improved disability data for policy, service design, and future research initiatives.² Although the proposed Long Range Plan attempts to address health and function, participation and community living, and technology in Strategy 1.2, Strategy, 1.3, and Strategy 1.4, respectively, by placing primary emphasis on the domain of employment, NIDRR is relegating participation and community living, health and function, technology, and disability demographics to minor domain status. The connection between these research domains and employment are not always so obvious. In fact, I believe that a project like the CULP-SCI, were it to be submitted under the new Long Range Plan, would not be funded because it did not address adequately employment and the association of the projects goals and employment are too circumstantial. As I stated above: I am a physician, a researcher, and a persons with a disability. I see first-hand the impact NIDRR-funded research has on individuals with disabilities and their families. As a person with a spinal cord injury, I have been personally impacted by the quality care provided through the SCI Model Systems program. Although I recognize the importance of improving employment outcomes for individuals with disabilities; I strongly urge NIDRR to also continue its research emphasis on health and function research, including medical rehabilitation research. To do otherwise would be short-sighted and could have dire consequences on employment outcomes and community participation in individuals with disabilities.

¹ National Institute on Disability and Rehabilitation Research (2009). Notice of proposed long-range plan for fiscal years 2010-2014 [On-line]. Available: Federal Register on Jan. 15, 2009 (see <http://www.ed.gov/legislation/FedRegister/other/2009-1/011509d.pdf>)

² National Institute on Disability and Rehabilitation Research (2006). Notice of final long-range plan for fiscal years 2005-2009 [On-line]. Available: Federal Register on Feb. 15, 2006 (see www.ed.gov/legislation/FedRegister/other/2006-1/021506d.pdf)

³ Consortium for Spinal Cord Medicine. Preservation of upper limb function following spinal cord injury: a clinical practice guideline for health-care professionals. *J Spinal Cord Med* 2005; 28:433-70.

CONTRIBUTOR: Trevor A. Dyson-Hudson, M.D.
Kessler Foundation Research Center
tdysonhudson@kesslerfoundation.net
(800) 248-3221 X2259

DCN: 362

RECEIVED: 3/16/2009

COMMENT: The American Occupational Therapy Association (AOTA) represents over 140,000 occupational therapists, occupational therapy assistants and students of occupational therapy. We appreciate the opportunity to comment on the proposed Long Range Plan (LRP) for Fiscal Years 2010-2014 (Plan). The notice was published in the Federal Register on January 15, 2009.

Five days before the inauguration of President Obama, the acting Assistant Secretary for Special Education and Rehabilitative Services published a notice in the Federal Register proposing a long range plan for NIDRR for Fiscal Years 2010-2014. The proposed plan modifies NIDRR's longstanding focus on the major life domains of employment, participation and community living, and health and function and instead specifies that the improvement of employment outcomes [will be] the focus of its long range plan for FYs 2010-2014. [74 FR at page 2566] Thus, the focus of research and development activities relating to the life domains of participation and community living, and health and function have been relegated to a less prominent status under the proposal. AOTA believes that this change undermines NIDRR's overall mission to improve participation of persons with disabilities of all ages in the home, community, school, as well as the workplace.

While AOTA recognizes the importance of getting or returning individuals to gainful employment we also understand the essential role of all three major life domains. AOTA believes it is important to target research toward practical goals and implementable strategies that will enhance outcomes for people with disabilities. Focusing the NIDRR strategic goal on employment would limit necessary and beneficial research in the other areas. Advancing research and development, knowledge transition and capacity building on all three life domains significantly improves the direct impact of research related to disabilities and rehabilitation and creates the ability to transition research from the academic environment to the fields of practice where such research can positively change lives.

As the national association representing occupational therapy, a profession dedicated to maximizing independence and function for people across the lifespan, AOTA recommends that NIDRR's new LRP recognize that gaps exist in knowledge, skills, policy, practice, and system capacity that prevent people with disabilities from having equal access to opportunities for employment, participation and community living, and health and function. The substantive focus of NIDRR's investment activity should be centered on the three major life domains of interest to NIDRR—employment, participation and community living, and health and function.

AOTA also urges consideration of the following comments on the importance of funding several specific areas to benefit the three major life domains. Research in the specific areas listed below would benefit one's ability to live independently in the community and sustain gainful employment. Research has shown that improving Independent Activities of Daily Living (IADLs) with certain populations results in higher rates of independent living, greater participation in the community, and ultimately fewer health care costs.

Driving:

The growing needs of drivers with disabilities are an important area for research and related training over the next five years. Research is needed in evaluating an individual's overall ability to operate a vehicle safely, rehabilitation strategies for correcting or minimizing problems, and into new types of equipment, including computerized functions, to enable the maximum number of individuals of all ages to safely participate in this activity critical to employment, socialization, and other life functions. Also important is the development of education materials to assure pre-professional and post-professional training fully addresses this need.

Home Environments:

Additional attention should be paid to the home as it is the hub for community and employment participation as well as the location of resources, devices and services that will help maximize independence and function. The LRP acknowledges the importance of choice for people with disabilities; nowhere is that choice more clearly defined by people with disabilities themselves than as related to their living environment and to the setting in which they choose to receive supportive devices and services. This need for emphasis is furthered by the increased needs of older Americans with disabling conditions who overwhelmingly desire to remain at home and age in place. A progressive agenda dedicated to choice for people with disabilities across the lifespan requires increased emphasis on the home as the primary location for activities undertaken by and in support of people with disabilities. Research is needed in application of new assistive devices to perform

home-related activities, in approaches to improving self-care skills, and designing and implementing structural and other home modifications. Another important area is to improve mobility assessments to assure that individuals obtain mobility devices that enhance their abilities to perform daily life functions in their homes.

Transition from School to Work:

Another area deserving of additional focus and emphasis within the LRP is transitioning special education students from school into the workforce and adult life. Occupational therapists are currently working with students under IDEA to facilitate more successful employment and participation outcomes, but the emphasis states and specific school systems place on this vital task varies greatly. Research is necessary in areas such as improving evaluations for capacity to work, developing training programs to maximize capabilities that can integrate with school curricula, and approaches to training in life-skills for independent living. Progress in this area to improve use of appropriate methods to facilitate positive transitions requires national leadership and must be supported through additional research to demonstrate the true effectiveness and importance of transition efforts to employment outcomes and independent living over the lifetimes of students with disabilities.

Mental Health Outcomes:

Increased focus should be given to achieving better outcomes for individuals coping with mental illness in all three life domains. Research is needed to go beyond the treatment of mental illness symptoms into the impact of services on the independence, function, and quality of life of people with mental illness. Research should focus on the improving the ability of individuals with mental illness to participate in activities ranging from self-care to community participation to employment. These are the outcomes that are important to people with mental illnesses and research must focus on what strategies and interventions can be successful in achieving them. Outcomes in this area should be evaluated longitudinally as different approaches may have a different impact on long-term change. Research in these areas will be invaluable to designing and implementing a continuum of care that maximizes participation in all life domains for people with mental illness.

Grant Process:

To improve the effectiveness of the LRP, AOTA, in conjunction with occupational therapists who are grantees of NIDRR, recommends that NIDRR work toward aligning its grant applications with that of other Federal agencies. This would streamline the process and facilitate NIDRR grantees' ability to transition applications among the other grant making agencies and maximize the amount of disability and rehabilitation research conducted to benefit people with disabilities. Such changes would also facilitate the increased involvement of NIDRR researchers and peer reviewers with other groups such as NIH.

Capacity Building in Research:

AOTA commends the plan for its emphasis on capacity building for research, particularly in regard to the recruitment of researchers from diverse academic backgrounds. A wide array of professional perspectives is essential to developing quality resources, devices and services for people with disabilities. In regard to increased diversity, the LRP discusses involvement and review of research and overall NIDRR activities by representative audiences of both researchers and consumers. This is particularly important in representation on the steering committee as well as on peer review panels. Including a mix of consumers, researchers, professionals and policy experts would be useful in moving the agenda established in the plan forward.

Development of New Measures of Participation:

AOTA fully supports efforts to better demonstrate the efficacy of programs designed to maximize participation by developing specific, more thorough, outcome measures. Quality, inclusive measures of participation, and intervention outcomes will enable disability and rehabilitation professionals to focus their efforts on evidence-based practices that deliver the most desired outcomes for people with disabilities.

In an effort to improve the overall effectiveness of the LRP, AOTA, in conjunction with occupational therapists who are grantees of NIDRR, recommends that NIDRR work toward aligning its grant applications with that of other Federal agencies. This would streamline the process and facilitate NIDRR grantees' ability to transition applications among the other grant making agencies and maximize the amount of disability and rehabilitation research conducted to benefit people with disabilities.

These comments were submitted in response to your request and for the purpose of improving the draft plan. AOTA requests that you give due consideration to these comments and incorporate them into the final Plan.

Thank you again for the opportunity to share our expertise in the area of maximizing independence and function as it relates to research and direct care for people with disabilities. We look forward to working with you to implement your Plan as it relates to occupational therapy and the people we serve.

CONTRIBUTOR: Christina A. Metzler, Chief Policy Officer
The American Occupational Therapy Association, Inc.
rkohl@aota.org

DCN: 363

RECEIVED: 3/16/2009

COMMENT: On behalf of the Brain Injury Association of New Jersey and the 1.4 million Americans who sustain a traumatic brain injury (TBI) each year, I am writing to express my deep concern regarding the proposed long range plan (FYs 2010-2014) for the National Institute on Disability and Rehabilitation Research (NIDRR). As proposed, NIDRR's plan will all but abandon the agency's longstanding commitment to research in the life domains of health and function as well as participation and community living, and instead, narrowly focus on employment. In general, we believe such an approach would undermine NIDRR's mission to improve participation of persons with disabilities of all ages in varied settings. Specifically, we believe the proposed approach would have long-lasting, detrimental effects on individuals with brain injury.

For people with brain injury, health and function research (including medical rehabilitation interventions) is more than an antecedent to employment. Indeed, the knowledge stemming from the health and function portion of NIDRR's research portfolio is vital to maintaining the overall health and wellness of individuals with brain injury and to maximizing their independence. Moreover, while such interventions do not always translate directly into changes in vocational outcomes, they do reduce dependency on public health and welfare systems and contribute significantly to the body of knowledge on TBI.

For example, the NIDRR's TBI Model Systems are the only source of non-proprietary longitudinal data on what happens to people with brain injury immediately after the injury and throughout their lifetimes. The Model Systems are a key source of evidence-based medicine, and serve as a proving ground for future researchers. TBI Model Systems researchers are currently working closely with the Department of Veterans Affairs to improve the treatment of returning service members with brain injuries.

Brain injury is not an event or an outcome. It is the beginning of a lifelong disease process. NIDRR should reaffirm its longstanding recognition that rehabilitation is not limited to short-term engagement for those individuals experiencing injuries or illnesses, but also includes ongoing management of chronic conditions as people move through their lives. NIDRR must maintain a broad portfolio of disability and rehabilitation research, including TBI-related Rehabilitation Research and Training Centers (RRTC's) and field-initiated investigations, which make similar contributions to ensuring the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with TBI, regardless of age.

In order to fully and faithfully carry out NIDRR's mission, the Brain Injury Association of New Jersey strongly urges the new Assistant Secretary for Special Education and Rehabilitative Services and the Director of NIDRR to restore the broad focus of NIDRR's research and development activities by recognizing the critical importance of all major life domains affecting persons with disabilities, i.e., participation and community living, health and function, as well as employment.

Thank you for your consideration.

CONTRIBUTOR: Barbara Geiger-Parker, President and CEO
Brain Injury Association of New Jersey
info@bianj.org
(732) 745-0200

DCN: 364

RECEIVED: 3/16/2009

COMMENT: We are writing in response to the National Institute on Disability and Rehabilitation Research (NIDRR) Notice of Proposed Long-Range Plan for Fiscal Years 2010-2014.¹ The proposed 2010-2014 Plan focuses primarily on one research domain, employment. This represents a significant shift from NIDRR's 2005-2009 Long Range Plan,² which placed equal emphasis on five research domains: employment; health and function; participation and community living; technology; and disability demographics. We believe that this shift of research focus could potentially diminish the impact of gains in the other 4 areas on employment, thus undermining the advancement of employment related research overall.

The approach NIDRR has taken for the past decade of research should be commended, as NIDRR has always recognized the critical interplay between medical rehabilitation research, health and functioning, and employment. NIDRR has served as the nation's lead federal agency on rehabilitation and disability research and is unique in that it recognizes the multifaceted nature of disability and maintains a broad portfolio of research. This research portfolio included the aforementioned five broad domains designed to most significantly impact the lives of persons with disabilities from multiple vantage points.

It is imperative that NIDRR continue to follow the pathway it has built over the last 3 decades. Importantly, the 2005-09 Long Range Plan continued NIDRR research efforts developed under the 1999-2003 Long-Range Plan by continuing to emphasize the major research domains of employment, participation and community living, health and function, and technology, while elevating the area of disability demographics to a major domain to reflect and reinforce the importance of improved disability data for policy, service design, and future research initiatives.² By placing primary emphasis on the domain of employment in the proposed 2010-2014 Long Range Plan, NIDRR is relegating participation and community living, health and function, technology, and disability demographics to minor domain status. In reality however, it is only through advancement in these other 4 domains that persons with disabilities will achieve maximal employment potential and opportunity.

One of NIDRR's great strengths has been its holistic approach to individuals with disabilities. Importantly, improvements in health and function, technology, and community participation are all critical antecedents to employment. A perfect example can be found in my own research. The main focus of my research is on validating cognitive rehabilitation strategies that truly work. The overarching goal of this is to return individuals with cognitive impairment to the workforce. However, as a prerequisite to making a treatment available to persons with disabilities, one must validate the treatment through a randomized clinical trial to ensure that 3rd party payors will reimburse for treatment. If 3rd party payors will not reimburse for the treatment, the treatment is often unavailable to the patient and they cannot work toward improvements in cognitive status and regaining meaningful employment. Thus, this research in health and function is vital to the advancement of employment opportunities in persons with disabilities. This is just one of many examples of the intricate relationship between the 5 domains emphasized by NIDRR for the past decade.

Our organization consists of rehabilitation researchers, physicians, policy makers, and individuals with disabilities. We have seen first-hand the impact NIDRR-funded research has on individuals with disabilities and their families. We recognize the importance of improving employment outcomes for individuals with disabilities. However, we strongly urge NIDRR to also continue its research emphasis on health and function research, including medical rehabilitation research. To do otherwise would be short-sighted and could have dire consequences on employment outcomes and community participation in individuals with disabilities.

CONTRIBUTOR: Nancy D. Chiaravalloti, Ph.D.
Kessler Foundation Research Center
nchiaravalloti@kesslerfoundation.net
(973) 530-3640

DCN: 365

RECEIVED: 3/16/2009

COMMENT: I am writing this letter to express my concern regarding substantial changes to NIDRR's research focus. In particular, I am troubled by the proposed shift towards vocational rehabilitation research at the expense of other areas in need of ongoing innovation and empirical inquiry, namely medical and psychosocial rehabilitation research. I believe that limiting the scope of NIDRR's support to one aspect of the disablement process is short-sighted and will severely curtail the ability of this important institution from serving the well-being of a considerable portion of American population in need of a diverse array of services-health care, education, employment, and accessible communities-to ensure their ability to live fulfilling and productive lives.

As a public health researcher, I investigate the social and environmental influences on health and well-being and therefore believe there is inherent value in maintaining a broad research focus that is inclusive of the medical, psychological, and social aspects of disability and health. Much of my research has focused on the social gradient of health, and how health disparities in vulnerable populations are wrought by limitations in resources and access, as well as powerful psychosocial forces such as discrimination and social exclusion. This area of inquiry has demonstrated a consistent association between socioeconomic indicators and health, and for this reason, I appreciate the need to study to barriers and design interventions that promote the participation of individuals with disabilities in the paid workforce. Implicit in this work, however, is the interaction between the physical, mental, and social factors that influence health and well-being. Neglecting one area in this triad would limit our ability to evaluate policy changes, particularly in regards to health and functioning.

CONTRIBUTOR: Amanda L. Botticello, Ph.D., MPH
University of Medicine and Dentistry of New Jersey
abotticello@kmrrec.org

DCN: 366

RECEIVED: 3/16/2009

COMMENT: I would like to share a few of my comments on NIDRR's Long Range Plan proposal to focus solely on Employment. I have worked with individual with traumatic brain injury since 1994 in a variety of capacities such as inpatient rehabilitation, outpatient rehabilitation, independent and community living skills, and vocational/employment services.

Return to employment is so important to many individuals after a TBI. However there can be so many challenges in other areas of the person's life that employment may need to be a longer term goal while the person works on challenges associated with traumatic brain injury. Many other focus areas such as health, function, community participation and technology are needed to assist individuals with TBI to get to a point where the goal of employment is a possibility. These focus areas are all interrelated to help an individual with TBI obtain and keep employment.

For many individuals with TBI employment may never be a possibility so keeping the focus broader with health, function, community participation, and technology will address needs of these individuals and quality of life issues.

Thank you for letting me share my comments.

CONTRIBUTOR: Sally Rickard, LRT/CTRS, CBIST
Carolinas Rehabilitation
sally.rickard@carolinashealthcare.org
(704) 355-2620

DCN: 367

RECEIVED: 3/16/2009

COMMENT: Introduction:

The American Therapeutic Recreation Association (ATRA) would like to offer the following regarding the long-term plan for fiscal years 2010 ' 2014 of the National Institute on Disability and Rehabilitation Research (NIDRR). The proposed long-range plan (LRP) is, in general, inconsistent with the historical mission of the NIDRR.

NIDRR Mission Statement:

It should be noted that, NIDRR's mission is to support research and related activities to generate new knowledge and promote its effective use in order to improve the lives of individuals with disabilities and their opportunities for full participation in society (Federal Register/Vol. 74, No. 10, January 15, 2009, p2564).

The proposed emphasis is incongruent with the general mission of the NIDRR as stated in agencies mission. To segment one of life's activities (i.e., improvement of employment outcomes) as the focus for the long range plan runs contrary to the agency's mission and to the holistic needs of individuals with disabling conditions.

Consistent with its original directive, the NIDRR should focus of its investment in research and development activities that maximize the participation of people with disabilities in the life of the community. By Congressional charge, the NIDRR's research and development activities should be centered on the three major life domains:

- Employment;
- Participation and community living; and
- Health and function.

The U.S. Department of Education's Strategic Plan for Fiscal Years 2007-12 reaffirms the Department's obligations to fulfill its congressional mandate to continue to support and monitor research leading to the development of interventions that support health and physical function, participation and integration into the community, and employment of individuals with disabilities. [See, 71 Federal Register, page 8173].

Congress charged NIDRR to serve as the primary agency to conduct disability and rehabilitation research related to employment and participation and integration into the community. Congress also directed NIDRR to serve as the primary agency supporting medical rehabilitation research that enhances the health and function of people with disabilities (i.e., research designed to enhance treatments that allow persons with traumatic brain injury, spinal cord injury, and other impairments to more fully participate in activities of daily living and related activities (e.g., recreation, education, community participation) in order to be part of society. In order to accomplish this objective, Congress expects NIDRR to lead the way in learning about new and better strategies to the improve community integration, health and function as well as the employment of people with disabilities. In fact, without each aspect, an individual cannot be successful in the employment domain. Without health and function, individuals with disabilities are less likely to participate in the community or in employment. Indeed, good health and function are essential to the achievement of each of these critical goals.

World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF):

The acknowledgement of the NIDRR's unique role in supporting rehabilitation research and development activities in context of the WHO's ICF as a reference should reflect the entire operational intent of the ICF. As reflected in the ICF, Body Structure, Body Function, Activities and Participation, and Environment are not limited to employment. In fact, the ICF addresses the whole person, all areas of functioning and full involvement in the community beyond the employment realm. The ultimate outcome for the ICF model is community participation in life including social, recreational, relationships, employment, education, etc. As indicated, NIDRR's role is to support activities that increase the self determination and participation of individuals with disabilities in the home, community, school and workplace (Federal Register, p. 2565). It is not restricted simply to employment. For NIDRR to set long-range goals based on one area of human activity is contrary to its mission, the scope of the ICF, and the needs of individuals with disabilities.

The focus of each of the objectives and accompanying strategies should be broader in context and should address the whole person. To imply that functional performance and capacity should be restricted to work or that activities and participation should be restricted to employment simply ignores sound rehabilitation goals

and practices that address the needs of an individual with a disability.

Consistent with input from the Disability Research and Rehabilitation Coalition, the American Therapeutic Recreation Association believes that the NIDRR's new LRP should:

- Reflect NIDRR's history and policy designating NIDRR as the lead federal agency on rehabilitation and disability research and the NIDRR's need to maintain a broad portfolio of research;
- Embrace the breadth and depth of critical domains impacting the lives of persons with disabilities (employment, participation and community living, and health and function);
- Address the needs of persons with disabilities of all ages, including infants, children, adolescents, older Americans as well as individuals of working-age;
- Recognize that rehabilitation is not only an intervention designed to fix someone who has been injured but includes ongoing management of chronic conditions;
- Build on NIDRR's current LRP;
- Include a planning model that assists in selecting those research activities most likely to lead to intermediate and long-term outcomes of interest;
- Build on the strong history of research accomplishments in all critical life domains; and
- Insist on the use of management strategies, including high-quality peer review, that result in support of rigorous research that is of utility to stakeholders.

Emphases of the NIDRR Foci

The NIDRR's mission and foci should be consistent with its historical mission. The NIDRR should emphasize on those activities that support research to improve the lives of people with disabilities. ATRA requests that the NIDRR's proposed long term plan focus attention on the major life domains consistent with the NIDRR's historic mission. Improving employment, community participation/community living, and health and function should each possess equal emphases under the NIDRR long range plan, as each contributes equally to the successful participation of individuals in life activities (i.e., work, education, social relationships, recreation, community participation).

CONTRIBUTOR: Thomas K. Skalko, Ph.D., LRT/CTRS
American Therapeutic Recreation Association
skalkot@ecu.edu
(252) 328-0018

DCN: 368

RECEIVED: 3/16/2009

COMMENT: I would like to comment on the proposed long range plan (FYs 2010-2014) for the National Institute on Disability and Rehabilitation Research (NIDRR) that was published in the Federal Register Volume 74 Number 10 on January 15, 2009. On page 2,566, it states that the improvement of employment outcomes [will be] the focus of its long range plan for FYs 2010-2014.

I fully support research development activities that focus on employment, but also believe that there is a continuing need for NIDRR to recognize and focus on health, function, participation and community living as distinct life domains. Without health and function, individuals with disabilities are less likely to participate in the community and employment. Infants, children, adolescents, and the elderly, as well as working age Americans with disabilities must benefit from the research and development activities conducted by NIDRR. NIDRR must maintain a broad portfolio of disability and rehabilitation research that, in the words of the Rehabilitation Act, is designed to maximize the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities of all ages.

Thank you for this opportunity to submit comments to NIDRR's next Long Range Plan.

CONTRIBUTOR: Yuying Chen, M.D., Ph.D.
University of Alabama at Birmingham
yychen@uab.edu
(205) 934-3320

DCN: 369

RECEIVED: 3/16/2009

COMMENT: These comments concern NIDRR's proposed Long Range Plan for FY 2010-2014 which was published in January, 2009. Like many of my colleagues in rehabilitation research, I have deep concerns that this new Long Range Plan, if enacted as written, will undermine NIDRR's role as the flagship agency for rehabilitation research. In prior years NIDRR has been guided by a mission to focus on multiple areas of importance to people with disabilities: employment, participation/ community living, and health and function, as well as a focus on technology and disability related demographic studies. This broad vision has served to support a balanced research portfolio intended to reduce the impact of disability at the levels of function, activity and participation; and to improve knowledge of the personal and environmental factors with a direct bearing on disability.

The new Long Range Plan represents an abrupt about-face in its exclusive focus on improvement of employment outcomes. Research targeting the needs of infants and children, the elderly and others retired from the workplace, and people for whom employment is not a viable outcome; research addressing health and function with no immediate effects on employment; and research on technology with no direct link to employment outcomes, will all be relegated secondary (if any) priority.

Although NIDRR claims that focusing the Plan on employment and employment outcomes will not prevent NIDRR from continuing the work it is currently funding, anyone who knows the breadth of NIDRR's current research portfolio knows that this claim states an impossibility.

Improvement of employment outcomes is an extremely important goal, but is not an appropriate single goal for the agency charged with funding rehabilitation research to meet the needs of all people with disabilities. With these comments I urge NIDRR to restore its scope to include research priorities focusing on health and function, participation and community life, and technology related to disability, in addition to the focus on employment outcomes. NIDRR should maintain a broad portfolio of disability and rehabilitation research that, in the words of the Rehabilitation Act, is designed to maximize the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities of all ages. This portfolio would include research intended to enhance health and function for people with traumatic brain injury, spinal cord injury, and other disabling conditions to maintain their basic wellness and enable their maximal participation in society.

NIDRR's Long Range Plan should be rewritten to make clear its intention to address the needs of people with disabilities of all ages and life situations, not only those of working age or those for whom employment is a reasonable goal.

CONTRIBUTOR: Tessa Hart, Ph.D.
Moss Rehabilitation Research Institute
thart@einstein.edu
(215) 663-6153

DCN: 370

RECEIVED: 3/16/2009

COMMENT: General

Comments and discussion offered in this section of our response are general in nature and do not address a specific section of the long range plan or address multiple sections of the plan. We have grouped these comments here at the beginning of our response to assist NIDRR in more easily addressing them.

Unwarranted Focus on Research

Discussion: The Long Range Plan (Plan) purports to be about the entire mission of NIDRR not a portion of it. Yet other than a passing reference to the Disability and Business Technical Assistance Centers (DBTACs) as a Program Mechanism, the statutorily mandated role of NIDRR as the Department of Education's primary technical assistance provider on the Americans with Disabilities Act (ADA) is missing from the Plan (29 USC 762 (b)(11)).

Recommendation: Re-draft the Plan to include the vital technical assistance mission throughout. Specific recommendations for inclusion of technical assistance language are also provided in individual section comments below.

Unwarranted Focus on Employment

Discussion: The Plan does not substantiate the focus placed on employment. While there is no doubt that employment is a critical issue for many people with disabilities, it is far from the only issue and does not impact a significant portion of people with disabilities at all.

Recommendation: Re-draft the Plan to provide a more balanced view of the multiple areas of importance in disability including health and function, community participation, employment, technology, and disability statistics.

Section Comments

I. Introduction

Discussion: The Plan Introduction incorrectly states the mission of NIDRR. The NIDRR mission statement must include its statutorily mandated obligation to provide technical assistance on the ADA.

Recommendation: Add the following sentence after the first sentence of this section: NIDRR's mission also includes coordinating activities with the Attorney General regarding the provision of information, training, or technical assistance regarding the Americans with Disabilities Act of 1990 (42 USC 12101 et seq.) to ensure consistency with the plan for technical assistance required under section 506 of such Act. Also add the words and technical assistance after the word research and before investments in the final sentence of this section.

Statutory Mandate

Discussion: The section on statutory mandate leaves out any discussion of the statutorily mandated role of NIDRR in providing technical assistance on the ADA. The term technical assistance is not defined among the list of key terms. The term knowledge translation is too narrowly defined. The Plan uses the term as only defined by the academic research community. That is, knowledge is only knowledge created through research and translation is only the movement of that research result into use. In the broader knowledge industry the term knowledge is understood to cover a much broader range of information generated from many sources. The ability to translate that knowledge for use is a vital one and may involve many activities such as reformulating the information in more usable formats for the intended audience. This aspect of knowledge translation is much closer to the role of the technical assistance activity of NIDRR. The term capacity building is too narrowly defined. In the Plan capacity building is limited to increasing infrastructure and individuals to perform research. Within NIDRR's role as the key provider of ADA technical assistance, capacity building also includes increasing infrastructure, networks, and individuals to deliver technical assistance.

Recommendation: Insert a paragraph after the first paragraph that identifies the statutory mandate at 29 USC 762 (b) (11) for NIDRR to provide technical assistance on the ADA.

In the paragraph beginning NIDRR implements incorporate technical assistance into the list of activities carried out by NIDRR to implement its statutory mandate and clearly define this term as including the development and dissemination of materials through a variety of methods and modes.

Broaden the discussion on knowledge translation to include the technical assistance aspects of knowledge translation rather than limiting the discussion to the academic research oriented definition.

Incorporate language into the discussion on capacity building that clearly states the need for increasing the infrastructure, networks, and individual capabilities to deliver technical assistance.

NIDRR's Unique Role

Discussion: This section of the Plan focuses entirely of the research portion of NIDRR's mission. It fails to acknowledge the element of NIDRR's mission for providing technical assistance on the ADA as unique in the federal government. Title V of the ADA establishes the need for individual departments of the government with roles in implementing this complex law to provide technical assistance on their particular section of the law. Only NIDRR was given the statutory responsibility for coordinating technical assistance across all titles of the ADA. In the final paragraph of this section, the Plan correctly discusses the unique role NIDRR plays in disability and rehabilitation research. As stated, individuals with disabilities face daunting challenges in employment, housing, public accommodations and services, education, transportation, communications, recreation, health services, and civic participation. Because NIDRR's budget represents the largest single Federal investment in disability and rehabilitation research, the agency must continue to fund projects that support this unique role. As currently drafted, the strategies offered to meet NIDRR's goals for FYs 2010-2014 are grossly duplicative of work being done by other OSERS offices and other Federal agencies. For example, Strategy 1.1.1 discusses job preparedness and skills. RSA currently directs a significant amount of money to vocational rehabilitation agencies to address this need. It is shortsighted at best to duplicate these efforts. This duplication does not represent principles essential to good stewardship of the public funds entrusted to NIDRR.

Recommendation: Include a paragraph in this section that discusses the unique role of NIDRR in providing technical assistance on the ADA across all titles of the ADA. NIDRR must redraft the Plan to revise outlined strategies that are not duplicative of activities and efforts of other agencies

NIDRR Accomplishments

Discussion: The Plan does a commendable job of characterizing many of NIDRR's accomplishments in a brief list in this section. However, the Plan does not provide any information on the nearly 20 years of technical assistance provided by the DBTACs. Considering the substantial financial commitment NIDRR makes to the DBTAC program, inclusion of the numerous accomplishments of the program is well advised.

Recommendation: Add one or more bullets to the list that captures information on the accomplishments of the ADA technical assistance program. This information can include total numbers of ADA technical assistance contacts made over the past 17 years, materials distributed, trainings provided, and number of organizations benefitting from DBTAC capacity building activities.

II. Need for Employment Focus

Discussion: The proposed LRP correctly highlights the NIDRR mission to support research and related activities to generate new knowledge and promote its effective use in order to improve the lives of individuals with disabilities and their opportunities for full participation in society. The LRP then goes on to discuss NIDRR's support of rehabilitation research that is more closely tied to longer term outcomes such as independence, community participation, and employment. Unfortunately, the Plan as drafted does not align with this mission as the introduction contends. In fact, the Plan blatantly contradicts the NIDRR mission by making the improvement of employment outcomes the focus of its long-range

plan for FYs 2010-2014. NIDRR's own APAER expert review panel on employment (2006) not only determined that the level of scientific excellence was generally inadequate, lacking scientific rigor and hypothesis testing; the overall productivity of the portfolio was disappointing and limited; that consumers would likely find the portfolio to be disappointing, but also found that there is an adequate number of awards in the Employment portfolio. An expansion of the employment-related research as suggested in the Plan ignores the findings of the NIDRR panel.

Consistent with this focus on employment, the Plan makes only passing references to health and function and community participation activities. In these limited instances, research in this area is primarily mentioned in the context of employment and employment outcomes. For example, the Notice describes the purpose of health and function research as critical antecedents to improved employment for individuals with disabilities. As stated above, the references to nonemployment related research, including health and function research is made almost reluctantly:

NIDRR proposes to use the goals, objectives and strategies described in the following section to guide the development of grant priorities in the coming years. Focusing the Plan on employment and employment outcomes will not prevent NIDRR from continuing the work it is currently funding. NIDRR will maintain a broad array of mandated programs it currently supports (e.g., the rehabilitation engineering research centers and spinal cord injury model systems program) and, where possible, will establish a link between each new priority it funds through these programs and employment outcomes.

We agree that NIDRR's role is to support activities that increase the self-determination and participation of individuals with disabilities in the home, community, school, and workplace. By focusing exclusively on employment outcomes, NIDRR is ignoring significant elements of lives of individuals with disabilities. An employment focus also ignores the needs of individuals across the lifespan. By focusing on the singular topic of employment which typically includes ages 18-65, the Plan ignores the needs of seniors and children with disabilities.

The Plan attempts to make a connection between research and related activities that are focused on employment's potential impact on health and function and community living. Specifically, the Plan posits that new knowledge that prepares individuals with disabilities to work, maintain employment, and progress in a career can also benefit individuals who choose not to work or who are unable to work, to the extent that those individuals may wish to otherwise participate in their community. The Plan then goes on to provide a single example of this phenomenon. To say the least, the Plan offers inadequate proof to justify the decision to focus solely on employment without going into enough detail on potential benefits for health and function and community participation. It is a blatant error to attempt to ascribe trickle down benefits of employment research to other areas of importance in the lives of people with disabilities.

Recommendation: NIDRR must redraft the Plan to expand the strategic focus on research and related activities that includes health and function, community participation, employment, technology, and disability demographic issues.

Employment Status of and Trends for Individuals with Disabilities

Discussion: The argument presented at the top of Federal Register page 2566 may be incorrectly interpreted. In fact, if the relative prevalence of disability by age does not change, and the overall percentage of people with disabilities goes up by 25% as stated, then one or more of the age groups must be increasing significantly in underlying size. This is certainly true of older Americans. Almost every statistic shows that the over-65 age group continues to grow dramatically. And, since this is also the age group with the highest prevalence of disability it is reasonable to argue that it may be the chief cause of the growth in overall prevalence of disability. The concern is that a significant portion of this age group is not part of the workforce. Thus arguing for a primary focus on employment makes very little sense. Rather it would seem that we should be arguing for a primary focus on disability and aging.

Even within the working population when one more closely examines the data it is easy to determine that a large portion of workers (or potential workers) with disabilities are individuals with developmental disabilities since this is the largest group of people with disabilities. Does this then mean we should focus much of our effort on this disability area to the potential exclusion of smaller disability types? Certainly not.

Recommendation: We strongly recommend that this entire section be reworked.

III. Strategic Focus: Focus of FYs 2010-2014 Long-Range Plan

Discussion: In this section, the Plan posits that by focusing on employment outcomes, NIDRR will address a critical area needed to improve the lives of individuals with disabilities and advance the work of RSA. NIDRR is its own distinct office within the U.S. Department of Education with a unique role in the world of disability and rehabilitation research as outlined in earlier sections of the Plan. While the work of NIDRR can complement and support the work of RSA, a long range plan that strives to advance the work of a sister office of the Department, at the detriment of the NIDRR mission, is short-sighted at best.

Recommendation: The Plan must be re-drafted to support the mission of NIDRR, not the work of RSA.

Goals

Discussion: This section of the Plan includes three goals. It does not include a goal for Technical Assistance which we have earlier argued is a key element of the mission of NIDRR, something that makes the organization truly unique, and has built a significant body of accomplishment for NIDRR.

Recommendation: We recommend adding a fourth goal titled Goal 4: Technical Assistance. The lead paragraph of this goal could be, Advance awareness, understanding, and implementation of the Americans with Disabilities Act through an aggressive program of technical assistance including information dissemination, referrals, training, and direct technical assistance. The objectives (4.1-4.3) could be increasing Awareness, Understanding, and Implementation. The further development of the strategies needed to achieve these objective should follow quite easily.

Goal 1: Research and Development

Discussion: Note that Goal 1 is not labeled as such.

Recommendation: Include the label Goal 1: with the Research and Development goal.

Objective 1.1

Discussion: As currently drafted, the strategies offered to meet NIDRR's research and development goals are grossly duplicative of work being done by other OSERS offices and other Federal agencies. For example, Strategy 1.1.1 discusses job preparedness and skills. RSA currently directs a significant amount of money to vocational rehabilitation agencies to address this need. Further, Strategy 1.1.2 discusses the improvement of employers' hiring, retention, and promotion of people with disabilities. The Department of Labor's Office of Disability Employment Policy works significantly in this area through several of its programs. It is shortsighted at best to duplicate these efforts.

Recommendation: NIDRR must redraft this section to revise outlined strategies that are not duplicative of activities and efforts of other agencies.

Objectives 1.2, 1.3, and 1.4

Discussion: In these sections, the Plan finally acknowledges a limited commitment to continued work on the domains of health and function, community participation, and technology. Unfortunately, all of these domains and the corresponding strategies are discussed in terms of employment outcomes for people with disabilities. Again, NIDRR's research and other activities in these domains must expand beyond employment to truly address the needs of the whole person.

Recommendation: NIDRR must redraft these sections to more fully address its mission across a variety of domains including health and function, community participation, employment, technology, and demographics.

Goal 2: Knowledge Translation

Discussion: The Plan defines knowledge translation as a process of ensuring that new knowledge and products gained through research and development will ultimately be used to improve the lives of individuals with disabilities and further their participation in society. It is our contention that this definition ignores key activities funded by NIDRR. For example, technical assistance, like that offered by the National Network of DBTAC ADA Centers, is a form of knowledge translation. The DBTACs take complex legal language and interpretations of the ADA and translates the knowledge to the appropriate audience. It is important to note that NIDRR has statutory obligation to provide this form of KT through the ADA technical assistance program (29USC76). Further, NIDRR's technical assistance activities also support the proposed KT strategies using the traditional research-based definition of KT. For example, the DBTACs support Strategy 2.3.2 by assisting with dissemination of knowledge generated through research and development by communicating in understandable language and formats that are accessible to all stakeholders, including policy makers. Because the DBTACs serve such a broad constituency at the regional level, research results from DBTAC research projects and results from other NIDRR-funded projects can be funneled to appropriate audiences using KT mechanisms.

Recommendation: NIDRR should add language to Goal 2: Knowledge Translation that appropriately expands the definition of knowledge translation to acknowledge the valuable role that technical assistance plays in KT.

Goal 3: Capacity Building

Discussion: Goal 3 suffers from the same narrow definition that was earlier discussed. Capacity building must include the increase in infrastructure and personnel to provide high quality technical assistance on the ADA throughout the USA. The ten DBTACs have aggressively pursued this goal for the past 18 years and as a result of their efforts have dramatically increased the numbers of individuals in small towns and communities throughout the country who can provide competent, credible assistance on the ADA. The DBTACs have developed key tools including distance learning techniques and a massive ADA Information Portal to aid in this capability. However, it is important that this effort continue.

Recommendation: We recommend adding two objectives to Goal 3: Objective 3.3: Improve the infrastructure that delivers ADA technical assistance to organizations, businesses, state and local governments, and people with disabilities throughout the USA, and Objective 3.4: Increase the number and capacity of individuals who are qualified to deliver high quality technical assistance on the ADA.

IV. Managing for Results - Program Mechanisms

Discussion: The Plan highlights that NIDRR has nine primary grant mechanisms for awarding funds and provides brief descriptions of these mechanisms. However, with the exception of SBIR grants, the Plan does not specifically specify NIDRR's statutory requirement and commitment to continue funding all nine grant mechanisms. The full program variety is vital to continue NIDRR's unique role in disability research and focus on the whole person.

Recommendation: Insert language in the Program Mechanisms section of the Plan following the first introductory sentence that clearly shows a commitment to continue funding of all of the identified grant mechanisms for FYs 2010-2014.

Peer Review Process

Discussion: While the Plan describes NIDRR's peer review process, it offers no strategies for improving the overall function, efficiency, and quality of NIDRR peer reviews. The recent IOM Committee on The Future of Disability in America recognized that while NIDRR has made many important improvements in its peer review process and ongoing oversight and management of NIDRR grants, important changes were still needed. For many years, NIDRR had been criticized in the research community for its poor peer review process and this criticism is damaging to NIDRR's overall reputation. Members of these peer review panels also recognize the need for improvement and innovation. Therefore,

this LRP offers an opportunity for NIDRR to offer specific strategies for addressing these deficiencies.

Recommendation: NIDRR should revise the section of the Plan regarding Peer Review Process to include key recommendations offered by the IOM Committee. These recommendations include:

1. Implementing a standardized review process across NIDRR's entire research portfolio;
2. Including explicit consideration of the past performance of those submitting proposals within the evaluation criteria for new applications;
3. The creation of a mechanism to allow revision and resubmission for investigator initiated proposals;
4. The assignment of proposal scores based on the quality of the entire proposal, similar to the approaches taken by NTH and NSF;
5. Limiting reviews by the lay consumer members of review panels to the nontechnical aspects proposal; and finally
6. Providing more educational feedback on the reviews, especially for young and first time investigators.

Monitoring and Evaluation

Discussion: Monitoring and evaluation are vital elements for the success of the Plan. However, the individuals being monitored and evaluated, the grantees, must be completely knowledgeable on the methodology by which NIDRR intends to conduct the evaluations. The peer review standards often do not include useful evaluation criteria for this topic. And, the grantees often exhibit limited understanding of true outcome oriented evaluation.

Recommendation: Ensure that rigorous peer review criteria requiring a draft logic model and analysis of near term and midterm outcomes are included in the review criteria for every grant. Establish a training program for current and prospective grantees that provide a complete understanding of the NIDRR logic model approach to evaluation and an understanding of outcomes compared to output.

CONTRIBUTOR: Jana Copeland, Ph.D.
Meeting the Challenge, Inc.
jcopeland@mtc-inc.com
(719) 444-0252 X109

DCN: 371

RECEIVED: 3/16/2009

COMMENT: Let me get this straight: As I read NIDRR's long range plan, I see that: (Objective 1) researchers are going to study me and other people with disabilities as well as or as part of their study of barriers, facilitators, and attitudes toward people with disabilities; then researchers are going to study better and more efficient ways to share what they've learned when they are studying me and other people with disabilities (Objective 2); and then researchers are going to study better and more effective ways of doing MORE research, presumably on and about me and other people with disabilities (Objective 3). Where's the rest of me?? And what happened to nothing about me without me?

Employment is important, no doubt about that; but so is what happens to me and other people with disabilities in the rest of the day as we try to participate and fully enjoy other aspects of being part of our communities.

What happens when a disability savvy public defender, whose mother and brothers have disabilities, needs to know if the ADA says that a witness with developmental disabilities is entitled to have a communication assistant to help him understand what is going on in court and, if so, who pays for it? I knew the answer: yes, effective communication; the State of Maryland-but referred her to the DBTAC: Mid-Atlantic Region to get the official information and supporting documents.

Where does a young woman with a physical disability turn when she is told that her service dog cannot accompany her into a Chinese restaurant? To the DBTAC: Southeast Region for materials explaining the rights of people with disabilities as well as the responsibilities of people who operate restaurants.

Research is important but so is the rest of NIDRR's mandate to (a) Support research, demonstration projects, training, and related activities to maximize the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities of all ages; and I don't see this other, essential, part reflected in the proposed Long Range Plan.

The DBTACs are the only NIDRR project that consistently work to provide the information, training, outreach and education that promote voluntary compliance with the ADA-and with the passage of the ADA Amendments Act, their assistance is even more vital in educating employers, businesses, state and local government entities and people with disabilities, yet this part of NIDRR's mandate and mission is reflected in the Long Range Plan only tangentially.

I suggest that NIDRR re-look at and revise its Long Range Plan to be more comprehensive and inclusive of the day-to-day concerns of individuals with disabilities by including training and technical assistance in support of the ADA and the ADAAG as a key component of its plans.

CONTRIBUTOR: Sally Weiss
Waynesville, North Carolina
smokymountainwoman8010@yahoo.com

DCN: 372

RECEIVED: 3/16/2009

COMMENT: On behalf of the Brain Injury Association of Texas (BIATX) and the 1.4 million Americans who sustain a traumatic brain injury (TBI) each year, I am writing to express my deep concern regarding the proposed long range plan (FYs 2010-2014) for the National Institute on Disability and Rehabilitation Research (NIDRR). As proposed, NIDRR's plan will all but abandon the agency's longstanding commitment to research in the life domains of health and function as well as participation and community living, and instead, narrowly focus on employment. In general, BIAA believes such an approach would undermine NIDRR's mission to improve participation of persons with disabilities of all ages in varied settings. Specifically, BIAA believes the proposed approach would have long-lasting, detrimental effects on individuals with brain injury.

For people with brain injury, health and function research (including medical rehabilitation interventions) is more than an antecedent to employment. Indeed, the knowledge stemming from the health and function portion of NIDRR's research portfolio is vital to maintaining the overall health and wellness of individuals with brain injury and to maximizing their independence. Moreover, while such interventions do not always translate directly into changes in vocational outcomes, they do reduce dependency on public health and welfare systems and contribute significantly to the body of knowledge on TBI.

For example, the NIDRR's TBI Model Systems are the only source of non-proprietary longitudinal data on what happens to people with brain injury immediately after the injury and throughout their lifetimes. The Model Systems are a key source of evidence-based medicine, and serve as a proving ground for future researchers. TBI Model Systems researchers are currently working closely with the Department of Veterans Affairs to improve the treatment of returning service members with brain injuries.

Brain injury is not an event or an outcome. It is the beginning of a lifelong disease process. NIDRR should reaffirm its longstanding recognition that rehabilitation is not limited to short-term engagement for those individuals experiencing injuries or illnesses, but also includes ongoing management of chronic conditions as people move through their lives. NIDRR must maintain a broad portfolio of disability and rehabilitation research, including TBI-related Rehabilitation Research and Training Centers (RRTC's) and field-initiated investigations, which make similar contributions to ensuring the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with TBI, regardless of age.

In order to fully and faithfully carry out NIDRR's mission, the Brain Injury Association of Texas strongly urges the new Assistant Secretary for Special Education and Rehabilitative Services and the Director of NIDRR to restore the broad focus of NIDRR's research and development activities by recognizing the critical importance of all major life domains affecting persons with disabilities, i.e., participation and community living, health and function, as well as employment.

CONTRIBUTOR: Jane Boutte
Brain Injury Association of Texas
info@biatx.org

DCN: 373

RECEIVED: 3/16/2009

COMMENT: The purpose of this email is to provide comments to the Assistant Secretary for Special Education and Rehabilitative Services on behalf of the Tennessee Disability Coalition regarding the proposed Long-Range Plan (FYs 2010-2014) for the National Institute on Disability and Rehabilitation Research (NIDRR).

The Tennessee Disability Coalition is an alliance of organizations and individuals who have joined to promote the full and equal participation of men, women and children with disabilities in all aspects of life. As a Coalition, we work together to advocate for public policy that ensures self-determination, independence, empowerment, and inclusion for people with disabilities in areas such as accessibility, education, healthcare, housing, and voting rights. The Coalition also serves as the ADA Network for Tennessee as part of the Disability and Business Technical Assistance Center-Southeast ADA Center.

Although we agree that there is a continued need to improve access to appropriate employment, retention of employment and career advancement for individuals with disabilities, we are concerned that the proposed Long-Range Plan too narrowly focuses on this aspect of people's lives as well as omits ADA technical assistance activities provided by the National DBTAC Network of 10 Centers. Furthermore, the current proposal does not appear to be in line with the new administration's disability agenda.

Because the ADA is a comprehensive and multifaceted law, it is often not easily understood by many. In order to more fully appreciate and understand the complexity of this law, up-to-date and accurate information about the ADA is critical. The Coalition continues to receive inquiries about the ADA Amendments Act of 2008 and the imminent changes to the ADA regulations and design standards. Therefore, it is vitally important to keep the public informed of its ADA rights, responsibilities, including court decisions. This demand can be met best through continued technical assistance activities.

The Tennessee Disability Coalition is concerned about the inconsistency between NIDRR's Long-Range Plan and the new administration's disability agenda (<http://www.whitehouse.gov/agenda/disabilities/>). The President's disability agenda outlines a comprehensive approach to improve the lives of individuals with disabilities. The plan addresses educational needs, health and mental health care needs, restoration of the ADA, and increased community living opportunities for individuals with disabilities. In order to effectively improve the lives of people with disabilities, a unified approach to public policy is warranted.

Therefore, we recommend that NIDRR re-draft the draft Long-Range Plan for Fiscal Years 2010 '2014 and make revisions to more accurately reflect Congress' intention when it established the agency. In order to be most effective, the Plan needs to reaffirm NIDRR's obligation to provide technical assistance in the form of information and training activities provided directly to individuals.

CONTRIBUTOR: Donna DeStefano
Tennessee Disability Coalition
donna_d@tndisability.org
(615) 383-9442

DCN: 374

RECEIVED: 3/16/2009

COMMENT: A concerted effort to focus the research and training activities of NIDRR is overdue. For too long, NIDRR has tried to do too much, for too many, with too few resources. This scattered agenda has frustrated external stakeholders and policymakers, and limited political and professional support for the agency. Until the broader disability community sees NIDRR as a means to reach its sociopolitical aspirations, it will not provide the firm political support needed to sustain and grow the agency.

Nearly a decade ago (with the support of a Switzer fellowship), I wrote an essay on disability studies and gerontology, where I contrasted the funding level and structure of the National Institute of Aging (NIA) with NIDRR (Kennedy, 2000). At the time, the NIA (one of the smaller National Institutes of Health), had a budget nearly 8 times as large as NIDRR's. My point was not that the NIA had too much money, but that NIDRR had far too little. Yet this was the high water mark ' NIDRR's current budget (now about \$106 million) has not even kept pace with inflation, and the NIA's budget is now nearly 10 times as large as NIDRR's. NIH funding has been flat for several years, but it has just received a \$10.4 billion boost from the economic stimulus bill. To the best of my knowledge, there are no similar supplemental funds on the horizon for NIDRR.

A clear emphasis on employment outcomes could help energize NIDRR stakeholders and build broader political support. I doubt that even the gloomiest activists involved with the passage of the Americans with Disabilities Act would have guessed that employment rates for people with disabilities would remain so intractably low over the past two decades. Focusing more of NIDRR's research and training activities on better understanding, and addressing, the multiple barriers to the U.S. labor market for people with disabilities is a worthy pursuit. It is certainly consistent with the agency's mission to improve the lives of individuals with disabilities and their opportunities for full participation in society.

The efficacy of many disability policies and programs to date has been hindered by simplistic definitions of disability and employment. For example, treating return to work as a single dichotomous variable obscures important differences in the duration, intensity and quality of employment (Baldwin & Johnson, 2001). Likewise, the Ticket-to-Work and Work Incentives Improvement Act (TWIIAA) focused on current SSI and SSDI beneficiaries, though early intervention for program applicants holds more promise for slowing the growth of program caseloads (Kennedy, Olney & Schiro-Geist, 2004). This area of research and policy development would benefit greatly if NIDRR became a focused partner in identifying and funding a more complex and coherent body of work.

It is important to note that disability program applications and enrollments tend to rise during periods of economic contraction. Given the depth and severity of the current recession, we can expect a substantial jump in program enrollments, and a concomitant jump in public hand-wringing about out of control entitlement programs. Any holistic perspective of employment outcomes is threatened in this environment by a narrower and more negative framing of cost-containment for disability benefits. NIDRR must take special care to protect the independence of its employment research portfolio.

In the current economic and political climate, there are a number of urgent employment issues that could truly benefit from a disability perspective. They include, but are by no means limited, to the following:

- Assessing the political and economic implications of de-coupling employment and health insurance coverage for people with chronic conditions and disabilities.
- Expanding models of reasonable accommodation for an aging workforce.
- Analyzing the additive and interactive effects of age and disability discrimination in the workplace.
- Addressing the personal assistance, family care, and transportation needs of workers with disabilities.
- Guaranteeing full inclusion of adults with disabilities in federal retraining and infrastructure programs.

The ideal NIDRR employment research agenda would further a more sophisticated and useful perspective of work disability that focuses on the whole person, whose ability to function and whose quality of life are dependent on the complex interaction of personal, societal, and environmental factors (Federal Register, 2009, p. 2565).

People of all ages, with and without disabilities, clearly face new opportunities and risks in this changing labor market: We simply cannot afford to continue to segregate access to the labor market by age and disability. Education will increasingly become a life-long process, instead of being concentrated at the beginning of the life course. Entry and exit from the wage labor market will become less regular, as

technological and sociological shifts lead to greater instability in the public and private sectors, necessitating a sturdy yet flexible set of income supports and retraining programs. Retirement will become less of an all or nothing proposition, as older people choose to remain in the workforce for social and economic reasons. (Kennedy 2000, p. 123)

NIDRR has more flexibility than any other national institute to move beyond the medical model of return to work and to concentrate its resources on identifying and addressing sociopolitical and socioeconomic barriers to employment. Centering itself on employment will position NIDRR to offer the disability community a unique research and policy agenda. This focused, targeted growth is the best approach to take NIDRR into its next phase of life as a thriving and relevant public agency.

References

Baldwin, M. & W. Johnson (2001). Dispelling the myths about work disability, National Academy of Social Insurance Working Papers,

http://www.nasi.org/usr_doc/Dispelling%20the%20Myths%20about%20Work%20Disability.pdf

Federal Register (2009). Notice of proposed long-range plan for fiscal years 2010'2014. 74 (10), 2564-2569.

Kennedy, J. (2000). Responding to the disparities between disability and aging research. *Journal of Disability Policy Studies*, 11(2), 120-123.

Kennedy, J., M. Olney & C. Schiro-Geist (2004). A national profile of SSDI applicants: implications for early intervention, *Journal of Disability Policy Studies*, 15(3), 178-185.

CONTRIBUTOR: Jae Kennedy, Ph.D.
Washington State University
jjkennedy@wsu.edu

DCN: 375

RECEIVED: 3/16/2009

COMMENT: General Comments:

NIDRR's Long Range Plan (LRP) stresses the need for improving employment outcomes for individuals with disabilities. Many individuals who acquire their disability at birth (e.g. cerebral palsy) or early in life (e.g. spinal cord injury) and have managed their lives successfully (including having gainful employment) for years will find that they are experiencing the effects of aging earlier than others or are developing secondary health conditions 1, 2. Individuals who acquire their disability for the first time later on in life are similarly faced with an impairment and disability and are also at risk for secondary health conditions. A chronic disease and disability can be a barrier to work capacity and participation in community and family life of those aging with and into disability. Therefore, effective therapy, preventive actions, and healthy lifestyles become more and more important 3. For example, a person with paraplegia from an early-in-life spinal cord injury (SCI) who begins to experience shoulder degeneration from years of wheelchair propulsion most certainly would benefit from lifestyle modifications that will reduce the wear and tear on his/her joints, as well as a simple exercise protocol that strengthens weak musculature and protects shoulder joints from further degeneration 4. A person with stroke can begin to incorporate the hemiparetic upper extremity into daily function through a multi-modality therapy program that combines several complimentary components such as capacity building and motivational enhancements combined with an intense task-oriented training program or a behavioral intervention using virtual reality (VR) task practice 5. Unfortunately, although such evidence-based techniques and interventions are currently available, they are seldom used for those who are aging with and into disabilities. Moreover, while research indicates that functional motor capacity can be improved, maintained or recovered via consistent participation in motor exercises and rehabilitation regimens 6, independent adherence to such preventative and rehabilitative programming outside the clinic setting is notoriously low 7.

Likewise, the cognitive, emotional and physical demands of a combat environment place enormous stress on even the best-prepared military personnel. The Operations Enduring Freedom and Iraqi Freedom (OIF/OEF) combat theatre, with its ubiquitous battlefronts, ambiguous enemy identification and repeated extended deployments, is anticipated to produce a significant number of returning American servicemen with posttraumatic stress disorder and traumatic brain injury. This indicates a significant mental health problem and highlights the need to address the healthcare needs and quality of life of members of the returning servicemen, intensively and with the best non-stigmatizing treatment tools available.

The LRP should fully emphasize the need for evidence-based strategies to establish the efficacies of home- and community-based therapeutic services that harness the benefits of well-founded cutting edge technologies. In particular, VR technologies designed to be integrated with specific programs of training for improving functional independence in the workplace, home and community. This approach is unique, and stands in sharp contrast to the more conventional use of technologies such as a device that can be used as a stand-alone assist for a specific task such as walking (e.g., a cane or walker). We propose a focus towards research and development that combines such technology with evidence-based behavioral approaches, such as muscle-specific exercises or sophisticated task-specific training protocols, which harness the benefits of meaningful task practice for sustained improvements in function and thereby foster participation in home, work and community life.

Specific Comments:

Another strategy for achieving Objective 1.3 might also explore existing models, methods, and strategies from other fields, specifically from ergonomics, to enhance health and function and enhance community participation.

Objective 1.4: Increase understanding of cutting-edge assistive technology and environmental factors that serve as facilitators of or barriers to improved employment and participation outcomes by supporting research and development on:

Strategy 1.4.2: Improving the availability, reducing the costs, and increasing the quality of workplace productivity enhancements, accommodations, and supports. might also stress the adoption of principles of Universal Design.

References:

1. Kemp BJ, Mosqueda L. Aging with a Disability: What the Clinician Needs to Know. Baltimore, M.D.: JHU Press; 2004.
-

-
2. Kemp BJ. What the rehabilitation professional and the consumer need to know. *Phys Med Rehabil Clin N Am* 2005;16(1):1-18, vii.
 3. Clark F, Azen SP, Carlson M, Mandel D, LaBree L, Hay J et al. Embedding health-promoting changes into the daily lives of independent-living older adults: long-term follow-up of occupational therapy intervention. *J Gerontol B Psychol Sci Soc Sci* 2001;56(1):P60-3.
 4. Mulroy S. Prevention and Treatment Strategies for Shoulder Pain in Persons with Spinal Cord Injury. American Spinal Injury Association. San Diego, CA: *Journal of Spinal Cord Medicine*; 2008.
 5. Stewart JC, Yeh SC, Jung Y, Yoon H, Whitford M, Chen SY et al. Intervention to enhance skilled arm and hand movements after stroke: A feasibility study using a new virtual reality system. *J Neuroeng Rehabil* 2007;4:21.
 6. Galvin R, Cusack T, Stokes E. A randomised controlled trial evaluating family mediated exercise (FAME) therapy following stroke. *BMC Neurol* 2008;8:22.
 7. Vincent C, Deaudelin I, Robichaud L, Rousseau J, Viscogliosi C, Talbot LR et al. Rehabilitation needs for older adults with stroke living at home: perceptions of four populations. *BMC Geriatr* 2007;7:20.
-

CONTRIBUTOR: Philip S. Requejo, Ph.D.
RERC on Aging with Disability
philip.requejo@verizon.net

DCN: 376

RECEIVED: 3/16/2009

COMMENT: The purpose of this letter is to provide comments to the Assistant Secretary for Special Education and Rehabilitative Services on behalf of Hearing Loss Association of America regarding the proposed long range plan (FYs 2010-2014) for the National Institute on Disability and Rehabilitation Research (NIDRR).

The Hearing Loss Association of America (HLAA) is the nation's leading consumer organization representing people with hearing loss. HLAA impacts accessibility, public policy, research, public awareness, and service delivery related to hearing loss on a national and global level. HLAA's national support network includes an office in the Washington D.C. area, 14 state organizations, and 200 local chapters. The HLAA mission is to open the world of communication to people with hearing loss through information, education, advocacy, and support.

In the two previous long-range plans covering FY1999 through the present, NIDRR has recognized that in order to carry out its mission, research and development activities must focus on three major life domains:

- Employment,
- Participation and community living; and
- Health and function (including medical rehabilitation interventions to improve function and health status research to improve overall health and wellness of people with disabilities).

The 2010-2014 Long Range Plan for NIDRR focuses on employment issues. We agree with NIDRR that there is a great need for employment-related research. But we must ask whether the new long term plan will be implemented so that the benefits will accrue to more than the working population of Americans. Research that will enhance access to employment, if interpreted broadly as we feel it must be, can have impact far beyond the workplace. If this long range plan is implemented in such a way that it incorporates the broad spectrum of needs of people who need employment without abandoning the equally important issues of community living and health and function, HLAA can support this long range plan.

In the 2010-2014 plan, NIDRR recognizes the need to focus on technology for access and function and disability demographics. We urge NIDRR to support research into the issues that impact people in the workplace, including:

- Transition from school to work
 - Research is greatly needed on the effect of untreated hearing loss and productivity, pay and promotion
 - Employment related health issues impacting employee productivity and supports, such as untreated hearing loss, and the relationship of stress related diseases such as diabetes and heart disease to hearing loss and productivity in the workplace
 - Research into technology that will provide better access in the workplace, including:
 - hearing aids that function better in noise and work better with mobile phone technology, as well as mobile phone technology itself, including the use of WiFi and Bluetooth, for the workplace that will better interface with hearing aids.
 - assistive listening devices that are affordable and functional in the workplace;
 - technology that will allow greater access to conference calling in the workplace;
 - captioning technology, such as speech recognition or other cutting edge technology that will make text to speech more affordable and accessible in the workplace;
 - technology that provides better alerting devices in the workplace in emergency situations;
 - Internet phone technology that will work better with hearing aids;
 - Research into the impact of the aging worker, including issues related to hearing loss and supports for people who must learn to cope with their hearing loss on the job
 - Research into the impact of health insurance coverage that does not provided for needed technology that will allow workers to keep their jobs and be productive on the job longer, such as hearing aids or assistive listening devices.
 - Research into disability demographics
 - Expanded funding for medical research in the areas of hearing, vision, and language
 - Research that would provide advances in technology to improve hearing in noisy environments,
 - Research on standards for acoustics in meeting places.
-

In December, 2008, HLAA signed on to a document presented to President Obama's transition team. That document included many issues that are pertinent for NIDRR, including:

- The need for new initiatives to create employment opportunities for people with disabilities including those who are deaf, hard of hearing, late-deafened or deaf-blind.
- The need for employment services to ensure that all programs and services are accessible in person and online to deaf, hard of hearing, late-deafened and deaf-blind persons.
- The need for funding for research about the impact of age-related hearing and combined hearing/vision loss on employee productivity and effective means to address that impact.
- The need for pre-employment, hands-on training, employment mentoring, and internship programs in the public and private sectors for deaf, hard of hearing, late-deafened and deaf-blind students transitioning from school to work.

We hope that NIDRR will consider inclusion of these concepts and research topics into the 2010-2014 Long Range Plan.

Thank you for the opportunity to comment on NIDRR's Proposed Long Range Plan for Fiscal Years 2010-2014.

CONTRIBUTOR: Brenda Battat, Executive Director
Hearing Loss Association of America
lhamlin@hearingloss.org
(301) 657-2248

DCN: 377

RECEIVED: 3/16/2009

COMMENT: My comments are regarding Section II. Need for Employment Focus By making the improvement of employment outcomes as the focus of its long-range plan for FYs 2010-2014, NIDRR may be potentially contradicting its role and mission. NIDRR's role under the Statutory Mandate among other things is to maximize the full inclusion and integration into society of individuals with disabilities of all ages. A focus on employment will naturally exclude several groups of individuals with disabilities who may also be retirees, minors, or individuals not seeking employment for a variety of reasons. Also, the major life domains identified by NIDRR are Health/Function, Employment and Participation/Community Living. By focusing on only 1 of the 3 major life domains, NIDRR will be actively limiting its scope in the much larger field of rehabilitation and the currently well-balanced approach of the whole person or the bio-psycho-social will be lost. Employment is truly an outcome that needs tremendous focus by all rehabilitation practitioners and policy makers, and NIDRR will continue to offer a leading edge in this focus area. The objectives and strategies listed by NIDRR in Section III of the Long Range Plan entitled Strategic Focus has a tremendous potential to generate numerous hypothesis-driven and intervention studies in the field of employment outcomes. But, sadly enough, that is not all we need.

Solving problems related to health and function is fundamental to rehabilitation and focusing on only one of many outcomes clearly is not the correct answer.

On March 19, 2008, NIDRR held a public meeting to solicit input to begin writing its new plan. During this meeting (I had the opportunity to view the Webcast), Dr. Jennifer Sheehy Keller, Acting Deputy Director of NIDRR, repeatedly clarified (1) that NIDRR was not going to replace medical rehabilitation research, (2) that a lot of misinformation was generated about the intent of NIDRR and its focus on employment, (3) that NIDRR was not ignoring health and function or community participation and (4) that investment in all NIDRR portfolios are of benefit to not only individuals with disability, but also to several other stake holders. It is disappointing to see that after all that convincing from NIDRR and the significant input it generated a year ago, the version from January 15, 2009 restates the focus on improvement of employment outcomes. If NIDRR is investing in all its portfolios as it did in the past, then there is a clear and urgent need to offer some clarifications in writing the final version of the long range plan.

CONTRIBUTOR: Radha Holavanahalli, Ph.D.
UT Southwestern Medical Center at Dallas, TX
radha.holavanahalli@utsouthwestern.edu

DCN: 378

RECEIVED: 3/16/2009

COMMENT: Over the past years, I have noted a change in NIDRRs planning and having reviewed the present long range plan I must express my concern. The present long range plan does little to focus on the important areas of health and function for those with disability. Among NIDRRs largest function is it's role in restoring health and function for those with disability. In a world that will require cost awareness and prudent decision making the need for medical rehabilitation research is critical. I strongly urge you to consider reevaluation of the present long range plan.

CONTRIBUTOR: Ross Zafonte, DO
Harvard Medical School
rzafonte@partners.org

DCN: 379

RECEIVED: 3/16/2009

COMMENT: On behalf of the Association of Rehabilitation Nurses (ARN) — a professional nursing organization, with just over 5,000 nurses, that promotes and advances professional rehabilitation nursing practice through education, advocacy, collaboration, and research to enhance the quality of life for those affected by physical disability or chronic illness — I am writing in support of the Disability and Rehabilitation Research Coalition (DRRC) submitted to you on March 10, 2009.

ARN is a member of the DRRC and, as such, fully supports their comments regarding the National Institute on Disability and Rehabilitation Research's (NIDRR) proposed long-range plan for Fiscal Year 2010-2014. We are, therefore, submitting this letter and incorporate the DRRC's comments by reference.

Thank you for this opportunity to submit comments to NIDRR's next Long-Range Plan.

The purpose of this letter is to provide comments to the Assistant Secretary for Special Education and Rehabilitative Services on behalf of the undersigned members of the Disability and Rehabilitation Research Coalition (DRRC) regarding the proposed long range plan (FYs 2010-2014) for the National Institute on Disability and Rehabilitation Research (NIDRR).

Set out below is a summary of our comments followed by a more in depth recitation of our position. The in depth recitation includes a brief review of the historical and policy context of NIDRR, a statement of principles that guided our review of the proposal, and our recommendations regarding the LRP mission statement, the inclusion of a logic model, goals, outcomes, focus, operational performance measures, and research agenda.

SUMMARY OF COMMENTS

Since the U.S. Congress established The National Institute on Disability and Rehabilitation Research (NIDRR) in 1978, it has served as the flagship federal agency on disability and rehabilitation research. NIDRR is a mission-oriented agency-its mission is to explore the interaction of individual characteristics and environmental factors and their effects on the participation of individuals with disabilities of all ages in the home, community, school, and workplace. NIDRR carries out its mission by generating new knowledge through research and development, promoting its effective use (knowledge translation), and building the capacity of institutions and individuals to conduct high quality research and development.

In the two previous long-range plans covering FY1999 through the present, NIDRR has recognized that in order to carry out its mission, research and development activities must focus on three major life domains:

- Employment,
- Participation and community living; and
- Health and function (including medical rehabilitation interventions to improve function and health status research to improve overall health and wellness of people with disabilities).

In addition, NIDRR has recognized the need to focus on technology for access and function and disability demographics.

On January 15, 2009, five days before the inauguration of President Obama, the acting Assistant Secretary for Special Education and Rehabilitative Services published a notice in the Federal Register proposing a long range plan for NIDRR for Fiscal Years 2010-2014. The proposed plan modifies this longstanding focus on the major life domains of employment, participation and community living, and health and function and instead specifies that the improvement of employment outcomes [will be] the focus of its long range plan for FYs 2010-2014. [74 FR at page 2566] Thus, the focus of research and development activities relating to the life domains of participation and community living and health and function have been relegated to a less prominent status under the proposal, thereby undermining NIDRR's mission to improve participation of persons with disabilities of all ages in the home, community, school, as well as the workplace.

Consistent with the focus on employment, the proposal only makes passing reference to health and function research and, when mentioned, health and function research is primarily mentioned in the context of employment and employment outcomes. For example, the Notice describes the purpose of health and function research as critical antecedents to improved employment for individuals with disabilities. Under research and development the proposed long-range plan articulates the following goal advance knowledge related to disability and rehabilitation through research and development, with particular emphasis on improving employment and participation outcomes for individuals with disabilities. Objective 1.1 focuses on

increasing knowledge of the factors that serve as facilitators or barriers to improved employment outcomes. Objective 1.2 focuses on increasing knowledge of the health and function factors that serve as facilitators of or barriers to improved employment and participation outcomes. [74 FR at pages 2566-2567]

As stated above, the references to non-employment related research; including health and function research is made almost reluctantly:

NIDRR proposes to use the goals, objectives and strategies described in the following section to guide the development of grant priorities in the coming years. Focusing the Plan on employment and employment outcomes will not prevent NIDRR from continuing the work it is currently funding. NIDRR will maintain a broad array of mandated programs it currently supports (e.g., the rehabilitation engineering research centers and spinal cord injury model systems program) and, where possible, will establish a link between each new priority it funds through these programs and employment outcomes.

We believe that there is a continuing need for NIDRR to recognize and focus on health and function as a distinct life domain. Without health and function, individuals with disabilities are less likely to participate in the community and employment. In the past NIDRR has appropriately recognized that there are many instances in which meaningful improvements in health and function may not always translate directly into changes in vocational outcomes. We also believe that there is a continuing need for NIDRR to recognize and focus on participation and community living as a distinct life domain.

So there is no misunderstanding about the position of the undersigned organizations regarding the appropriate focus of NIDRR's research and development activities, we want to make it perfectly clear that we also fully support research and development activities that focus on employment. It is critical for NIDRR to advance employment-related innovations (both demand and supply side), improve delivery of services at the systems level (with particular emphasis on improving the effectiveness of services authorized under the Rehabilitation Act), and advance public policy that makes work pay (work incentives and the seamless delivery of services and supports). What we are saying is that if NIDRR is to accomplish its congressionally-mandated mission, it must continue the longstanding policy of focusing its research and development activities on all major life domains, including participation and community living, health and function, as well as employment.

Infants, children, adolescents, and the elderly, as well as working age Americans with disabilities must benefit from the research and development activities conducted by NIDRR. NIDRR should reaffirm its longstanding recognition that rehabilitation is not limited to short-term engagement for those individuals experiencing injuries or illnesses, but also includes ongoing management of chronic conditions as people move through their lives. NIDRR must maintain a broad portfolio of disability and rehabilitation research that, in the words of the Rehabilitation Act, is designed to maximize the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities of all ages.

In order to fully and faithfully carry out NIDRR's mission, we urge the new Assistant Secretary for Special Education and Rehabilitative Services and the Director of NIDRR to restore the broad focus of NIDRR's research and development activities by recognizing the critical importance of all major life domains affecting persons with disabilities, i.e., participation and community living, health and function, as well as employment.

IN DEPTH RECITATION OF COMMENTS

HISTORICAL AND POLICY CONTEXT

Historically, Congress established NIDRR to serve as the Nation's lead federal agency on rehabilitation and disability research and, as such, to maintain a broad portfolio of research designed to maximize the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities of all ages. [See, Section 200 of the Rehabilitation Act of 1973, as amended] Since 1978 and in the two most recent long-range plans, NIDRR has recognized that its mission is to generate new knowledge and promote its effective use to improve the abilities of people with disabilities to perform activities of their choice in the community, and also to expand society's capacity to provide full opportunities and accommodations for its citizens with disabilities.

NIDRR also has recognized the substantive focus of its investment in Research and Development related to maximizing the participation of people with disabilities. More specifically, research and development activities are centered on the three major life domains of interest to NIDRR:

- Employment;
-

- Participation and community living; and
- Health and function.

[See, 71 Federal Register at page 8173] The U.S. Department of Education's Strategic Plan for Fiscal Years 2007-12 reaffirms the Department's obligations to fulfill its congressional mandate to continue to support and monitor research leading to the development of interventions that support health and physical function, participation and integration into the community, and employment of individuals with disabilities. [See, Page 31, emphasis added]

In sum, Congress directed NIDRR to serve as the lead and primary agency to conduct disability and rehabilitation research related to employment and participation and integration into the community. Congress also directed NIDRR to serve as the lead and primary agency supporting medical rehabilitation research that enhances the health and function of people with disabilities i.e., research designed to enhance treatments that allow persons with traumatic brain injury, spinal cord injury, and other impairments to more fully participate in activities of daily living and be part of society. If we are to achieve the promises of the Americans with Disabilities Act, Congress expects NIDRR to lead the way in learning about new and better strategies to the improve community integration, health and function as well as the employment of people with disabilities.

Consistent with Congressional intent, NIDRR historically has recognized that there are many instances in which meaningful improvements in participation and community integration may not always translate directly into vocational outcomes, especially for infants, children and adolescents and older Americans who are not working. NIDRR also has recognized that there are many instances in which meaningful improvements in health and function may, but do not always translate directly into changes in vocational outcomes. The continuing need for medical rehabilitation research is to improve function and the need for health status research is to improve overall health and wellness of persons with disabilities. Without health and function, individuals with disabilities are less likely to participate in the community and in employment. Indeed, good health and function are essential to the achievement of these other very important goals.

Based on our understanding of congressional intent, as reflected in our review of NIDRR's historical and policy context, we have developed a set of principles to help guide the development of our comments regarding the content of NIDRR's new LRP.

- NIDRR's new LRP should:
- Reflect NIDRR's history and policy designating NIDRR as the lead federal agency on rehabilitation and disability research and NIDRR's need to maintain a broad portfolio of research;
- Embrace the breadth and depth of critical domains impacting the lives of persons with disabilities (employment, participation and community living, and health and function);
- Address the needs of persons with disabilities of all ages, including infants, children, adolescents, older Americans as well as individuals of working-age;
- Recognize that rehabilitation is not only an intervention designed to fix someone who has been injured but includes ongoing management of chronic conditions;
- Build on NIDRR's current LRP;
- Include a Logic Model to help select those research activities to be supported that are most likely to lead to intermediate and long-term outcomes of interest;
- Build on the strong history of research accomplishments in all critical life domains; and
- Insist on the use of management strategies, including high-quality peer review, that result in support of rigorous research that is of utility to stakeholders.

MISSION

Consistent with Title II of the Rehabilitation Act, we recommend that NIDRR's new LRP include the following mission statement:

The mission is to generate new knowledge and promote its effective use to improve the abilities of people with disabilities of all ages to perform activities of their choice in the home, community, school, and workplace and also to expand society's capacity to provide full opportunities and accommodations for its citizens with disabilities.

LOGIC MODEL

We recommend that NIDRR's new LRP recognize that significant gaps exist in knowledge, skills, policy,

practice, and system capacity that prevent people with disabilities from having equal access to opportunities for employment, participation and community living, and health and function. The substantive focus of NIDRR's investment activity should be centered on the three major life domains of interest to NIDRR-employment, participation and community living, and health and function. In addition, the Logic Model should include two additional domains-technology for access and function and disability demographics.

With respect to employment, for many people with disabilities, employment that is challenging, fulfilling, and adequately compensated is the ultimate rehabilitation outcome. Employment shapes the lives of individuals with disabilities who are interested in and qualified for workforce participation. At the individual and systems level success should be measured in terms of acquisition, improvement, and enhancement of skills, productivity, earnings, job retention and advancement, and benefits. NIDRR should advance employment-related innovations that contribute to success at work and subsequent improvements in quality of life in education, home, and community. Research supported by NIDRR must continue to focus on improving the implementation of employment-related activities supported by OSERS, including the Rehabilitation Services Administration (RSA).

With respect to participation and community living, NIDRR should focus on the extent to which people with disabilities are participating in the community in a manner that is meaningful to them and support research into programs and services that expand the scope of participation of people with disabilities, especially those with the most severe disabilities. NIDRR should sponsor research to improve knowledge of individual and societal level factors that may serve as barriers to, or facilitators of, participation among all people with disabilities. Research may include evaluation of specific participation-promoting programs, interventions and products, as well as development of methods, measures, and theories to enhance scientific rigor of these evaluations.

With respect to health and function, research on maximizing health and function among people with disabilities is critical to the achievement of NIDRR's mission and the associated higher-order goals of employment and community participation. Functional ability reflects the complex interaction between individuals and the environments in which they live. In conceptualizing health and function research to improve the lives of individuals with disabilities, NIDRR should posit a growing need for research on medical rehabilitation interventions to improve function and for health status research to improve overall health and wellness of people with disabilities.

GOALS

The LRP should identify strategic goals that communicate NIDRR's main themes and directions. The goals should reflect NIDRR's mission and align with the targeted outcomes arenas depicted in the Logic Model. We recommend that NIDRR's new LRP include the following four goals:

- Research and Development (R & D)-Advance knowledge about disability and rehabilitation through research and development.
- Knowledge Translation (KT)-Increase the use of research and development knowledge to improve policy, practice, behavior and systems related to disability and rehabilitation.
- Capacity Building (C-B)-Increase the capacity of individuals (particularly those with disabilities) and institutions to conduct high-quality disability and rehabilitation research and development.
- Management-continuously improve NIDRR outcomes through effective management, monitoring and use of program data.

OUTCOMES

Long-term outcomes arenas. NIDRR's long-term outcomes should focus on eliminating disparities between people with and without disabilities in employment, participation and community living, and health and function. These long-term outcomes should serve as critical anchor points guiding all strategic planning and research management efforts.

Short-term outcomes arenas. Within the logic model, there should be four short-term outcome arenas corresponding to NIDRR's investments in four functional arenas. These functional arenas are R&D, KT, C-B, and management corresponding to NIDRR's four strategic goals. R&D should be further divided to reflect three stages of knowledge development-

1. discoveries;
 2. new or improved theories, measures, or methods; or
 3. interventions, products, devices, and environmental adaptations.
-

FOCUS

At the heart of NIDRR's mission should be the support of research to improve the lives of people with disabilities. We recommend that NIDRR's new LRP focus attention on the major life domains as set out in the Logic Model. Improving employment outcomes should be a major concern of NIDRR as should improving the functioning of OSERS' programs related to employment, including vocational rehabilitation and programs related to the education of transition-age youth with disabilities. Similarly, improving participation and community living outcomes (including maximizing choices for persons with disabilities as they select their dwellings, transportation, and life activities) should be a major concern of NIDRR. Furthermore, improving health and function outcomes should be a major focus of NIDRR research as advances in this domain are the foundation for attaining outcomes related to employment and participation and community living.

OPERATIONAL PERFORMANCE MEASURES

The future research agenda for NIDRR should rest on the long-term outcomes depicted in the Logic Model, which call for the elimination of disparities in employment, increasing participation and community living, and improving health and function for people with disabilities and the general population. However, because achieving this desired end-result requires changes in the overall condition of people with disabilities that go beyond the reach of the Institute's mission, it is necessary to articulate an additional set of more operational performance measures with respect to employment, participation and community living, and health and function.

RESEARCH AGENDA

The research agenda, as we suggested, must reflect the three critical life domains of individuals with disabilities-employment, participation and community living, and health and function. The proposed LRP focuses on the research agenda related to the employment domain. Set out below are our comments regarding the participation and community living and health and function domains.

NIDRR's research agenda in the domain of participation and community living should be designed to strengthen the scientific basis of policies and practices aimed at enhancing participation among people with disabilities by providing information and analyses that improve understanding of participation levels among individuals with disabilities and the multiple barriers and facilitators of their participation. NIDRR's research agenda should also strengthen participation-related research and practice by increasing the availability of validated theories, measures, and methods. These theories, measures, and methods should improve data sources and estimates, and should enable better identification, evaluation, and prediction of the factors that facilitate or impede participation and community living. These improvements should enhance the credibility of research and thus increase the utilization of research findings.

As stated above, maximizing health and function of people with disabilities is critical to the achievement of community participation and employment. Functional ability reflects the complex interaction between individuals and the environment in which they live. Accordingly, NIDRR should conceptualize and examine issues of health and function at both the individual and systems levels.

Specifically, the health and function agenda at the individual level should fund research that supports the development and evaluation of new interventions, products, devices, and environmental adaptations aimed at improving the health status and functional abilities of people with a wide range of disabling conditions. These interventions should address the needs of people who are aging with disability, with particular emphasis on minimizing secondary health conditions and disabilities. These interventions should also address the unique needs of infants, children and adolescents with disabilities. NIDRR should also fund research that leads to the development of the next generation of valid and reliable measures of health and functional status among people with disabilities.

At the systems level, NIDRR-supported research should focus on the structure, organization, and delivery of health care and medical rehabilitation services. Also at the systems level, NIDRR should study access to health care and rehabilitative services, and the complex delivery systems used for those services. Individual level research should focus on the development and testing of new interventions that improve functional and health outcomes for individuals. As already stated, in conceptualizing health and function research to improve the lives of individuals with disabilities, NIDRR should posit a growing need for research on medical rehabilitation interventions to improve function and for health status research to improve overall health and wellness of people with disabilities.

At the systems level, NIDRR should also fund research that will generate new knowledge about the systematic causes and consequences of substandard access to rehabilitation, healthcare, and mental health

care services for people with a wide range of disabling conditions. This research will identify and evaluate the effectiveness of specific service delivery approaches and payment models aimed at minimizing physical, social, and economic barriers to the full spectrum of health, mental health, and rehabilitation services that are needed by people with disabilities. In addition, research is needed to support the development of evidenced-based practice methods that are consistent with rehabilitation treatment practices that currently exist in the field and with the rehabilitation research methods used to develop new assessments and interventions.

Overall Agenda-NIDRR's research agenda in the area of health and function should be designed to increase the number of validated new or improved methods for assessing function and health status; increase the number of interventions, products, and devices demonstrated to be efficacious in improving health and function outcomes in targeted disability populations; and increase understanding of the underlying structures and processes that facilitate or impede equitable access to rehabilitation and physical and mental healthcare by people with disabilities.

Thank you for this opportunity to submit comments to NIDRR's next Long Range Plan.

Sincerely,

American Academy for Physical Medicine and Rehabilitation

American Academy of Orthotists and Prosthetists

American Association of People with Disabilities

American Association of Spinal Cord Injury Psychologists and Social Workers

American Congress of Rehabilitation Medicine

American Medical Rehabilitation Providers Association

American Occupational Therapy Association

American Physical Therapy Association

American Therapeutic Recreation Association

Amputee Coalition of America

ARA Institute

Association of Academic Physiatrists

Association of Rehabilitation Nurses

Brain Injury Association of America

Christopher and Dana Reeve Foundation

National Association for the Advancement of Orthotics and Prosthetics

National Association of Rehabilitation Research Training Centers

National Association of State Head Injury Administrators

National Council on Independent Living

National Multiple Sclerosis Society

National Spinal Cord Injury Association

Paralyzed Veterans of America

United Spinal Association

CONTRIBUTOR: Jeremy R. Scott
Association of Rehabilitation Nurses
info@rehabnurse.org
(847) 375-4710

DCN: 380

RECEIVED: 3/16/2009

COMMENT: Upon reviewing NIDRR's draft Long-Range Plan for Fiscal Years 2010-2014, I ask you to consider the following 3 comments when redrafting the Plan:

1. Please include ADA technical assistance activities provided by the National DBTAC Network of 10 Centers in NIDRR's Long-Range Plan. The NC Council on Developmental Disabilities is actively involved as the state affiliate for the DBTAC: Southeast ADA Center. ADA Technical Assistance and Training is an on-going need in our state. Just this month, we addressed ADA issues of accessible public transportation, accessibility of emergency shelters, and effective communication at tax sites. Now that the ADA Amendments Act of 2008 are law, combined with the impending major changes to the ADA regulations and design standards, technical assistance and training services offered through the DBTACs are more important than ever before.
2. Please expand the focus of the Long-Range Plan beyond Employment to include ADA issues related to full participation in the community. Employment continues to be a major issue for persons with developmental disabilities. However, for people with disabilities to achieve full participation in society, the full continuum of inclusion including community participation, transportation, housing education, and health and function must also be addressed.
3. Please align NIDRR's Long-Range Plan with President Obama's 4-point disability agenda. I am concerned about the inconsistency between NIDRR's Long-Range Plan and the new administration's disability agenda (<http://www.whitehouse.gov/agenda/disabilities/>). President Obama's 4-point disability agenda outlines a comprehensive approach to improve the lives of individuals with disabilities. The plan outlines the need for efforts designed to:
 - 1) improve education;
 - 2) restore the ADA;
 - 3) promote health and mental health care; and,
 - 4) increase community living opportunities for individuals with disabilities including improved employment outcomes.

We believe that a unified commitment from all agencies to carry out an overall disability agenda as directed by the current administration is the most effective way to improve the quality of life for people with disabilities. Thank you for your time and consideration.

CONTRIBUTOR: Karen Hamilton
NC Council on Development Disabilities
khamil1214@aol.com

DCN: 381

RECEIVED: 3/16/2009

COMMENT: Expansion of NIDRR's Narrow Focus

NIDRR's three domains do address critical issues faced by people with disabilities: employment, participation and community living, and health and function; however, there are excellent reasons to place a far greater emphasis on the second domain, participation and community living: Home and community based service programs are gaining popularity and their use is likely to expand; in the next several decades the long term service system will face unprecedented demand as baby boomers acquire disabilities and as boomers with disabilities age; at the same time the systems will be stressed even more due to limited resources and the available workforce will diminish; and, finally, community living is a foundation for employment.

Emphasizing employment to such a great extent without a significant emphasis on community living leaves the impression that we truly believe that a job in the community is more important than living in the community when indeed getting a job is entirely dependent upon having appropriate supports beforehand.

There is a pressing need for solid research to inform policy, change practice, and improve outcomes in participation and community living. More specifically '

- Rigorous research to identify program models that best support outcomes of independence, self direction, and community integration. Many new HCBS programs have been initiated through the Real Choice Systems Change initiative of the Centers for Medicare & Medicaid Services. To date, program effectiveness assessment has been formative and descriptive. Research is needed which will identify the aspects and characteristics of HCBS programs that best support community living outcomes.
- Research to support implementation of HCBS programs through new initiatives of centers for independent living. CILs can serve as a primary resource for those with disabilities, as well as older persons who acquire disabilities, and identification, testing, and refinement of effective service delivery models within the self directed approach practiced by centers can serve an important means to expand and improve HCBS.

Management and Administration

In the areas of management and administration, we make the following recommendations:

Requests for proposals and application submission criteria describe activities in such a way as to make it appear that research is limited to experimental design. Valuable information for the field can be secured through other methodologies: surveys, policy research, and community-based participatory research. We urge that NIDRR broaden its focus on the kinds of research activities it welcomes, encourages, and supports.

Two months notice or less for NIDRR's RFPs is not sufficient; a significantly longer lead time is needed, both in terms of announcing priorities and making the actual requests for proposals. This approach has the effect of favoring incumbents and forcing diminished quality in applicant planning in effect closing the door to innovation. Awards are too small across all of the funding mechanisms. Acknowledging that the need for rehabilitation research exceeds the amount of funding available, NIDRR should limit the scope of work or increase funding to fewer projects. Focusing adequate resources into key areas holds the promise of creating real advances through NIDRR's efforts.

Also, echoing Annual Performance Assessment Expert Review, NIDRR could consider a shift in focus to building capacity, rather than funding the research itself. This is an approach used by the Veterans Administration to good results in research programs.

Omission of Technical Assistance

The LRP does not acknowledge NIDRR's responsibilities to provide information, training and technical assistance on the Americans with Disabilities Act and also provides no direction regarding:

1. how its technical assistance project (DBTAC-ADA Centers) will be managed
2. necessary resources will be allocated and
3. activities will be coordinated with other federal efforts on ADA implementation.

However, NIDRR is specifically charged with carrying out these activities. According to 29USC76, NIDRR and the secretary are charged with 2: (11) coordinating activities with the Attorney General regarding the provision of information, training, or technical assistance regarding the Americans with Disabilities Act of 1990 (42 U.S.C.12101 et seq.) to ensure consistency with the plan for technical assistance required under

section 506 of such Act (42 U.S.C. 12206) <http://law.justia.com/us/codes/title29/29usc762.html>

NIDRR's omission in its LRP of technical assistance on the ADA is a major concern for ILRU, as we believe technical assistance is, and continues to be, critical to implementation of the Americans with Disabilities Act. The ADA supports the independence and well-being of persons with disabilities in accessing all of the benefits and privileges of society. It promotes health and function and increases community living opportunities for individuals with disabilities including improved education and employment outcomes. In Title V of the ADA, Congress mandated that executive branch agencies develop comprehensive dissemination and technical assistance plans to assist entities and individuals covered by the law in understanding their ADA rights and responsibilities (PL 101-336, 1990). The ADA is a complex piece of legislation. Its complexity has been compounded by court cases, regulatory rulemaking and Congressional action in passing the ADA Amendments Act. There continues to be a tremendous need for DBTACs that can provide direct technical assistance to consumers and any entity or individual with rights or responsibilities under the law. The provision of technical assistance through the DBTACs also provides NIDRR with important insight on emerging issues and disabilities and can assist NIDRR with policy development.

The increasing numbers of individuals with disabilities protected by the law and the new issues that continue to emerge with each new demographic demand that new, innovative technical assistance interventions need to be crafted to insure full inclusion of everyone. The DBTACs have worked with these groups and can continue researching and developing resources and strategies that will improve their integration and access to society.

Youth with Disabilities

The fastest growing groups of individuals with developmental disabilities are those with autism. It affects 1 to 1.5 Americans annually and there is between 10-17% annual growth in that number. New technical assistance strategies targeted to meet the unique needs of this population need to be developed.

Students in K-12 with IEP's range from 13% -25% in different school facilities and across school districts. Forty-four percent of this population have learning disabilities. Students with language (16%) intellectual (9%) and emotional disabilities (7%) account for the remainder of this group (U.S. DoE, 2001-2002, IDEA). Most students with disabilities enroll in public two-year community colleges. Eleven percent of these students self-report having a disability. However, most students do not report disability at the post secondary level. More and more students with disabilities are enrolling in colleges. There is a strong correlation between educational attainment and employment. This group needs effective, ongoing technical assistance and resources to assure equal access to educational opportunities.

Working Age Population

Of the working age population, arthritis, back problems, heart disease and respiratory problems are the leading causes of disability. The labor force is aging with an annual growth rate of individuals 55 and older projected to be nearly four times that of the overall labor force (Center for Labor Market Studies, 2008). Older workers have a much higher incidence of disability which indicates a critical need for increased focus on the workforce accommodation needs of this population.

Returning Veterans from Iraq and Afghanistan Conflicts

Veterans with disabilities are re-entering the workforce, educational institutions, and re-engaging in their communities. These veterans deserve to participate and be integrated into all areas of American society. Issues of particular relevance to this group are physical access to the built environment and accommodating head injuries in work and educational settings.

Individuals with Cancer

There are 9.8 million cancer survivors in the United States, according to a report by the Centers for Disease Control and Prevention (CDC). The number of cancer survivors in this country has increased steadily for all cancers combined. As improvements are made in cancer detection, treatment and care these numbers will increase. Sixty-four percent of adults whose cancer is diagnosed today can expect to be living in five years. Technical assistance activities need to be directed to this emerging group of cancer survivors.

<http://www.cancer.gov/newscenter/pressreleases/MMWRCancerSurvivorship>

Misalignment with Administration's Disability Agenda

ILRU has strong concerns regarding the inconsistency between the LRP and the new administration's disability agenda. President Obama's 4-point disability agenda outlines a comprehensive approach to improve the lives of individuals with disabilities. The plan outlines the need for efforts designed to:

-
1. improve educational opportunities;
 2. restore the ADA;
 3. promote health and mental health care;
 4. increase community living opportunities for individuals with disabilities including improved employment outcomes. <http://www.whitehouse.gov/agenda/disabilities>

The LRP must reaffirm NIDRR's obligation to provide technical assistance in the form of information and training activities provided directly to consumers. We also recommend that the revised LRP better align its goals, objectives, and philosophy with those of the new administration.

Conclusion

We at ILRU offer these comments in a spirit of support and cooperation to help NIDRR become a significant force for much needed change for those of us with disabilities. With this plan NIDRR has significantly narrowed its mission and direction, displaying a stunning Lack of discernment of the range of issues which contribute to health, independence, integration, and employment. This myopic perspective holds the potential to place long range limits on the programs and services that should be positioned to create expanded opportunities. The programs NIDRR can offer under the restrictive plan, as presented, will not provide the much needed change that people with disabilities expect and deserve. This LRP, as drafted, will not support the full panoply of the needs of persons with disabilities in the United States. We at ILRU urge NIDRR to expand the scope of the plan to again encompass the three domains of employment, participation in community living and health and function.

CONTRIBUTOR: Marisa Demaya
DBTAC Southwest ADA Center at ILRU, a program of TIRR Memorial Hermann
mdemaya@bcm.tmc.edu
(713) 520-0232

DCN: 382

RECEIVED: 3/16/2009

COMMENT: This letter is in response to the NIDRR LRP.

It has been a long time since we communicated and it is now difficult to reopen dialogue with a negative response to the proposed Long Range Plan of NIDRR based on what appears to be a shift in the previous priorities of this valuable agency's contribution to medical rehabilitation and training.

I am advocating for a new or well revised LRP, that takes into consideration the recommendations of the Disability Rehabilitation Research Coalition (DRRC) signed by many Professional and Consumer organizations in response to the proposed NIDRR Long Range Plan published in the Federal Register January 15, 2009.

We encourage the critical emphasis of the original importance of Health and Function as one of the three major components of NIDRR's important mission. Rewriting the Plan would clearly reinstate the congressional intent for NIDRR role in the three areas clearly stated by Congress. The direction and interpretation of the LRP will impact the agency's direction, funding priorities and ultimately the lives of people with disability over the next five years. Under the current Plan, medical rehabilitation research and all it encompasses appears to be clearly diminished.

Employment and community participation are most worthy research directives and areas that NIDRR grantees have contributed greatly however medical rehabilitation research enables those who are disabled to participate and contribute to their families, community and society.

I wear many hats, among the most important is the hat that put me where I have been over the past 33 years is that as the mother of a severely disabled daughter now turning 50 having been injured at the age of 15 in 1975. NIDRR was a young agency and we were first meeting and communicating back in 1980. The hat I was wearing then was as the founder and Exec Director of the NHIF, now the Brain Injury Assoc of America. The model systems in TBI were not yet established and the first TBI RRTC's were in their infancy. It was an act of overwhelming advocacy from a young emerging field that caused the growth of the TBI systems in the early 80's.

It is now, with that kind of passion rekindled, I speak personally for the vital importance of the future of medical rehabilitation research leading to excellence of clinical care, a generation of new knowledge and the increasing capacity in the field that I again advocate. Over the past 9 years, I have been the Neurotrauma Outreach Coordinator at Spaulding Rehabilitation Hospital in Boston, MA which is affiliated with Harvard Medical School. I also serve as the Chair of the Public Policy and Legislation Committee of the American Congress of Rehabilitation Medicine (ACRM) and one of its representatives on the Disability Rehabilitation Research Coalition (DRRC) and recently named Honorary Chair of the Sara Jane Foundation committed to Pediatric Brain Injury.

Since 1981 I have been a staunch supporter and ADVOCATE for NIDRR, RSA and OSEP. Indeed for OSERS. However during the past few years there has been a distressing turn in philosophy and direction of NIDRR away from medical rehabilitation research that appears very troublesome. That new direction is clearly revealed in the proposed LRP. It can be interpreted as an arrow through the heart of medical rehabilitation research and the training of young researchers. As the lead federal agency on disability research, NIDRR must maintain a portfolio that leads to maximizing current interventions and seeks new innovations to promote health and function.

The field depends on NIDRR to work with grantees to discover, identify, ascertain, and prove new treatments, technologies and methods of whatever it may be to prove the most efficacious of treatment protocols and technologies and the effectiveness of emerging neuro-pharmacology. There is growing concern and need to prevent deterioration of physical, cognitive and sensory systems of individuals with disabling conditions from those injured and affected by disease from birth to old age. This must be a priority and one of major thrusts of NIDRR. What are the impacts of disabling conditions over a lifetime when preventive care and maintenance is too frequently denied or inaccessible? The list of potential and needed research questions within the opportunities of medical rehabilitation is long indeed! The current plan omits discussion. Again the DRRC recommendations should be taken seriously.

Successful employment and real community reentry must depend on the health, well being of and functional capacity of every person with any kind of disability, particularly severe, whether from injury or disease. The critical issues of psycho-social and behavioral consequences of life changing impairments have long been

areas of NIDRR research over the past 3 decades. Major contributions to individuals due to that investment have made an impact especially in the areas of TBI and SCI. This focus of research must continue in light of the changing demographics resulting in a dramatic increase of people living longer with disabling conditions. The enormity of numbers of young men and women injured in Iraq and Afghanistan, who will eventually be living in their home communities and looking to the civilian sector for assistance and employment should benefit from research funded by NIDRR.

Thank you for this opportunity to respond to this most important request for comments.

CONTRIBUTOR: Marilyn Price Spivack
Spaulding Rehabilitation Hospital
mspivack@partners.org
(617) 573-2055

DCN: 383

RECEIVED: 3/16/2009

COMMENT: Thank you for soliciting input regarding changes to the NIDRR Long Range Plan. Thank you also for attending to some of the comments submitted last year as the plan was being finalized. I am writing to express three continuing concerns about this plan: 1) NIDRR should not just be about employment outcomes; 2) the direct support workforce crisis must be addressed; and 3) we cannot effectively monitor progress without a robust disability statistics program.

Employment is not the only important outcome. The plan should give more consideration to other types of participation outcomes.

In NIDRR's previous plan (2005-2009) published Feb 15, 2006, several different domains of research are described including: employment, health and function, technology for access and function, participation and community living, and disability demographics (p. 8166).

In the January 2009 plan, the strategic focus, goals, objectives and strategies emphasize employment outcomes disproportionately. For example, in the Research and Development goal, objective 1.1 focuses only on employment outcomes and ignores other outcomes important to children, working age adults, and seniors with disabilities and their families.

While helping people with disabilities achieve high quality employment outcomes is very important, other outcomes are also important to persons with disabilities. For those currently living in institutions, community living and participation is a necessary prerequisite to employment. Institutionalized persons ages 18 to 64 years need first to live in places that allow, support, and encourage community living, social inclusion, self-determination, societal participation, and self-advocacy. As the New Freedom Initiative Executive Order noted, unjustified isolation or segregation of qualified individuals with disabilities through deinstitutionalization is a form of disability-based discrimination prohibited by Title II of the ADA of 1990 (Bush, June 19, 2001). The recent media stories about abuse in Texas State Schools, and about the Iowa poultry farm slave labor camps for persons with IDD provide new examples of the continuing need for research on community living and inclusion itself as a basic human need. A focus on employment without adequate attention to access to community living, social inclusion, self-determination, societal participation and self-advocacy would ignore some of the most important needs of persons with disabilities.

The 2003 NIDRR co-sponsored National Goals Conference identified five national commitments and goals that promise access to and support for integrated community lives for people with ID/DD (Lakin, Gardner, Larson & Wheeler, 2005). Those goals include:

- To allow people with disabilities to live in and participate fully in their communities
- To ensure that people with disabilities will have satisfying lives and valued social roles
- To help people with disabilities and their families choose supports they need and control how resources are used to provide them
- To provide people with disabilities with stable, skilled support providers when needed
- To provide people with disabilities with health, safety, and supports to manage life's risks (p.182)

We have a long way to go in realizing these goals. NIDRR should continue its commitment in its long range plan to achieving these five goals along with the goal of high quality employment. To have employment as the only or most prominent goal ignores the needs of persons with disabilities ages 65 and older who have retired, persons of working age who are living in nursing homes, state institutions, ICF-MR facilities or other institutions and children. To focus on employment to the exclusion of other key outcomes is to ignore the reality that even persons who work full-time spend only 2080 of their 8760 hours each year at work (24%). Much of life is about what happens during those other hours. I would respectfully request that NIDRR maintain a broader set of priorities that encompass access to community settings, participation and community living, valued social roles, choices about supports, access to stable skilled direct support professionals, and supports to manage life's risks in addition to its stated priority of access to employment.

Research and Development Objective 1.2 seems to be a bit broader, in that strategies 1.2.1 and 1.2.3 could be construed to support research on outcomes other than employment. However strategy 1.2.2 targets only employees with disabilities ignoring the health and wellness needs, quality and availability of health benefits, and disability management for the 62% of Americans with disabilities who are not employed (based on the employment rate cited on p 2566), and all of the children with disabilities, and persons with disabilities who

are not of working age or are not able to work due to disability or illness.

In Goal Area 2 (Knowledge Translation) the objectives and strategies are stated in a way that accommodates translation of knowledge about both employment and participation outcomes. This is a welcome inclusion. However, in Goal Area 3 (Capacity Building), Objective 3.1 capacity building for research and development, two of the four strategies mention only employment research (3.1.2 and 3.1.3). Objective 3.2 includes strategies that apply across a range of outcomes important to persons with disabilities.

Research and Development Objective 1.3, facilitators of or barriers to improved outcomes, allows for research on participation outcomes other than employment. This is good since we definitely need research on promoting self-determination and participation in social roles, reducing social isolation, enhancing communication skills, and increasing independence and community living. Likewise, we continue to need more research on policy and systems changes that enhance self-determination and choice, support family caregiving and personal assistance services, and increased availability of home and community based services that promote independence, safety, security and community living. Based on this, I would expect to see competitions across all nine of NIDRR's program mechanisms focusing on participation outcomes such as community living, self-determination not only those focusing on employment outcomes. This plan is silent on the need for research, demonstration, knowledge translation and capacity building around finding, training and keeping family caregivers and direct support professionals hired by families, individuals with disabilities and service organizations.

Research and Development Objective 1.3 does not attend to the substantial barriers facing community participation due to the changes in the availability of both family caregivers and paid direct support professionals. In 2006, ASPE submitted a report called: The supply of direct support professionals serving individuals with intellectual disabilities and other developmental disabilities: Report to Congress. That report concluded the following:

One of the challenges facing the U.S. in the 21st century will be to ensure that individuals of all ages receive, throughout their lives, the health and social support services they need to live with dignity as fully included members of our society. For the estimated 4.3 million Americans of all ages with intellectual disabilities and/or developmental disabilities (ID/DD) living in residential settings, their own homes or with members of their families, ensuring access to and quality of direct support professionals (DSPs) is key to realizing national goals established in the Americans with Disabilities Act, the Developmental Disabilities Assistance and Bill of Rights Act, and other statements of national purpose with regard to the full citizenship and inclusion of individuals with ID/DD.

In June 2003 there were an estimated 874,000 full-time equivalent (FTE)* DSPs assisting individuals with ID/DD in group residential settings, family homes, their own homes, community jobs, vocational and day training settings, and other service settings. The Department of Health and Human Services (HHS) estimates that by 2020, the number of DSPs needed to meet LTSS demand will grow to approximately 1.2 million FTEs providing an estimated 1.4 million individuals with ID/DD with needed residential, vocational and other supports. Between 2003 and 2020 HHS anticipates that the number of DSPs needed to provide for the growth of LTSS for individuals with ID/DD will increase by about 323,000 jobs, or roughly 37%. This increase will be largely due to population increases, increases in life expectancy among persons with ID/DD, aging of family caregivers, and expansion of home and community-based services. This increase in demand will be occurring at a time when the labor supply of adults age 18-39 years, who traditionally have filled these jobs is expected to increase only by 7%.

These projections indicate that meeting the future demand for DSPs will be extremely difficult to achieve through enhanced recruitment alone. It will be critically important to improve also the retention of existing DSPs along with efforts to attract new ones. (p.vi).

The report went on to say:

It is not possible to consider the quality of community services for people with ID/DD without attending to the status of the direct support workforce providing those supports. The quality and stability of DSPs are of fundamental importance to the well-being of people with ID/DD. As the U.S. Secretary of Labor, Elaine Chao, observed on September 24, 2002, The paraprofessional long-term care workforce is the cornerstone of America's long-term care system. The fundamental, long-term challenge is how to develop a committed, stable pool of employees who are willing, able and skilled to provide quality care. (p. 22).

If NIDRR fails to recognize the scale of this crisis or if it decides not to continue to fund projects designed to address this crisis, there will simply not be enough people to provide the supports need to accomplish those

goals. Between 2010 and 2014, NIDRR should continue to support research, training and demonstration projects on the effective implementation of intervention strategies to help individuals with disabilities and the organizations that support them to find, train and keep people (whether family members or paid direct support professionals) to support them.

We cannot effectively monitor progress without a robust disability statistics program that allows sufficient analysis of policy relevant groups within the disability population.

NIDRR's current long-range plan used data from the 2000 U.S. Census to describe persons with disabilities. However, those data do not include sufficient specificity to monitor the status and outcomes of persons with a variety of types of disabilities regarding important policy goals. The only large study which allowed specific robust identification of persons with intellectual and developmental disabilities was the National Health Interview Survey- Disability Supplement fielded 1994-1996. NIDRR funded a multiyear program of research that mined the results of that data to describe in rich detail the prevalence of ID/DD and the characteristics and service needs of persons with ID/DD in the U.S. non-institutionalized population (e.g., Larson, Lakin, Anderson, Kwak, Lee, Anderson, 2001). NIDRR also funds an RTC focused on disability statistics. It is very important that programs like these continue so that we have answers for our Congressional and Legislative bodies when they ask, How many people does this policy change affect? or How many people are there with xx (e.g., ID/DD, Autism, TBI)? Of course one outcome that we need to monitor is whether people with disabilities have high quality employment. But even that question cannot currently be adequately answered for some groups of persons with disabilities (especially persons with ID/DD) because such persons cannot be reliably identified within existing Census-Based surveys, or because they are intentionally excluded because they require proxy respondents or significant communication adaptations to respond (e.g., Altman, Brown, Hendershot, Larson, Weathers, & Chevarley, 2006). Sadly, we know a whole lot more about persons with ID/DD and other disabilities in nursing homes and institutions than we do about the vast majority who are in the non-institutionalized population. In its long range plan, NIDRR should reaffirm its commitment to working with the Interagency Committee on Disability Statistics and with researchers to develop, maintain and use data systems to identify persons with various types of disabilities and to assess our nation's progress toward accomplishing our important policy goals for these individuals.

The American Community Survey offers some helpful information about persons with disabilities in general, but its descriptors simply are robust enough to allow a separate analysis for persons with intellectual or other developmental disabilities compared with same age persons with disabilities whose disabilities were acquired in early or late adulthood. The long-range plan notes NIDRR's accomplishments in recent decades in improving national data and statistics. The need for this work has not ended. Therefore, I would request that the strategic focus and goals of the 2010-2014 long range plan also attend to gaps and needs related to national data and statistics on a broad array of participation outcomes in ways that allow researchers, policy makers, and other stakeholders to use those national data and statistics to examine the needs, and outcomes of strategic subpopulations of persons with disabilities, including but not limited to persons with intellectual and developmental disabilities.

References

- Altman, B., Brown, S.C., Hendershot, G., Larson, S., Weathers, B., & Chevarley, F. (2006, July). From theory to questions: Considerations of disability definition and survey purpose in survey implementation. State of the Art Conference on Developing Improved Disability Data. Washington DC: Interagency Subcommittee on Disability Statistics. National Institute on Disability and Rehabilitation Research, Office of Special Education and Rehabilitative Services.
- Lakin, K.C., Gardner, J., Larson, S.A., & Wheeler, B.Y. (2005). Access to support for community lives, homes and social roles. In K.C. Lakin & A.P. Turnbull (Eds.). National goals and research for persons with intellectual and developmental disabilities (pp. 179-215). Washington, DC: American Association on Mental Retardation.
- Larson, S.A., Lakin, K.C., Anderson, L, Kwak, N., Lee, J.H., Anderson, D. (2001). Prevalence of mental retardation and developmental disabilities: Estimates from the 1994/1995 National Health Interview Survey Disability Supplements. American Journal on Mental Retardation, 106, 231-252.
- Office of the Assistant Secretary for Planning and Evaluation (2006). The supply of direct support professionals serving individuals with intellectual disabilities and other developmental disabilities: Report to Congress. Washington, DC: Office of Disability, Aging and Long-Term Care Policy, ASPE, U.S. Department of Health and Human Services. John Drabek, Project Officer.
-

CONTRIBUTOR: Sheryl A. Larson, Ph.D.
University of Minnesota
larso072@umn.edu
(612) 624-6024

DCN: 384

RECEIVED: 3/16/2009

COMMENT: This letter conveys my comments to the Assistant Secretary regarding the proposed Long Range Plan (LRP - FYs 2010-2014) for the National Institute on Disability and Rehabilitation Research (NIDRR). I feel that it is important to express my concerns about the posted NIDRR LRP, as posted for comment. In the last two NIDRR long range plans (FY1999 - present), NIDRR set forth a mission focused on three life domains: employment, participation, and health and function. I have concerns that the previous balance of activities will be lost if the proposed LRP goes forward without extensive modification. The proposed plan is too focused on employment, with inadequate attention being focused on the critical precursors to successful employment for persons with disabilities. Moreover, I am concerned that the plan as drafted does not adequately reflect constituent input, including consumers with disabilities, as well as the insight from the disability research community. I make these observations from the perspective of someone who has specialized in employment-related disability research for 15 years, as well as someone who has benefited from NIDRR research funding in the past.

I believe that it is unfortunate and misguided that the percentage of successful closures in vocational rehabilitation (VR) and the baseline employment rate for persons with disabilities nationally are often cited as failures of our VR systems. Although not specifically cited in the LRP as problematic or in need of change, I believe that current levels of successful closure for persons with disabilities in the VR system stand as a testament for the hard work and success of these state-based employment programs. The fact that VR can post similar successful closure rates year after year, with an increasingly severely-disabled population and more limited budgets at their disposal constitutes a remarkable success story accomplished through a passion to their mission. This is even more notable in light of the continually increasing percentage of persons with disabilities who experience secondary conditions with psycho-social components (e.g., mental illness - substance use disorder). Moreover, we have known for some time that statutory conditions, such as rules for social security and Medicaid obviously factor greatly into the base line employment rate for persons with disabilities, yet the research into this area has been less than successfully translated into laws or regulations by our legislators. This is not a rationale for more research, but a call to action for our legislative arm of government to better respond to what is already known. This fundamental issue should not be ignored by NIDRR or used as an excuse for doing additional research on issues that existing NIDRR sponsored research could actually help to address at the present time. However, somewhat contrary to this point, if the LRP is to be applicable to employment issues, the specific needs for research into transportation alternatives, health care resources and alternatives, benefits analysis and offsets, psycho-social conditions, and educational alternatives must be more adequately considered and enumerated.

The LRP as drafted also does not consider the question of disability employment research capacity and infrastructure. The fact is abundantly clear to me as a disability researcher - at the current time there are limited numbers of researchers capable of rigorous research into disability employment issues. Without greater emphasis on researcher infrastructure development (and reflected in the LRP), a shift to employment research for NIDRR would undoubtedly result in a granting of more projects and funds to the limited number of disability employment researchers who currently exist. Although this might prove beneficial to me and a few others, I doubt it would be in the long term interests of NIDRR or persons with disabilities. The LRP must consider infrastructure development of the researcher community if this employment focus is to be successful.

It is abundantly clear that America is aging, and the needs of our now extended employment lifetime and protracted engagement with employment settings must be better researched - for the sake of persons with disabilities as well as for America in general. However, persons with disabilities will best be served if we preserve a combined research agenda on the participation and health/function issues that contribute to our many challenges as disability researchers. In fact, no focus on employment and job success can neglect these other legs of the three-legged stool.

Yes, it is important for NIDRR to research employment-related innovations (both demand and supply side), including all aspects of employment as defined by the Rehabilitation Act. However, to truly accomplish this goal, NIDRR needs to continue their focus on community participation and health and function as well. Ignoring either of these will be a disservice to persons with disabilities, and it will ignore the reality of the many current challenges to persons with disabilities.

CONTRIBUTOR: Dennis Moore, EdD
Wright State University
dennis.moore@wright.edu
(937) 775-1484

DCN: 385

RECEIVED: 3/16/2009

COMMENT: The West Virginia ADA Coalition has successfully educated people with disabilities, state and local government entities, employers and the general public under the generous grants from NIDRR through the DBTAC. We provide technical assistance, trainings, public awareness and other ADA related services. The WV ADA Coalition currently has 42 members throughout the state. Members include people with disabilities, family members and representatives of the major WV agencies and organizations that work with and/or represent people with disabilities such as the WV Division of Rehabilitation Services, the WV ADA Office which is housed in the Governor's Department of Administration, all of the state's Centers for IL, the SILC, the DD Council, the Mental Health Consumers Association, the Olmstead office, the WV Human Rights Commission and many others.

Members of the WV ADA Coalition have review the Draft Long Range Plan and are concerned about the inconsistency between the plan and the new administration's disability agenda.

President Obama's 4-point disability agenda outlines a comprehensive approach to improve the lives of individuals with disabilities. His plan outlines the need for efforts designed to:

1. improve educational;
2. restore the ADA;
3. promote health and mental health care; and,
4. increase community living opportunities for individuals with disabilities including improved employment outcomes.

NIDRR's proposed plan fails to adequately address the administration's disability agenda. We believe that a unified commitment from all agencies to carry out an overall disability agenda as directed by the current administration is the most effective way to improve the quality of life for people with disabilities.

Of major concern is the focus on employment. While the employment of people with disabilities is a major issue, NIDRR's full mission is more broad, as posted on their website: "to support research and related activities to generate new knowledge and promote its effective use to improve the lives of people with disabilities and their opportunities for full participation in society."

Focusing exclusively on employment neglects the concept of "full participation." For people with disabilities to achieve full participation in society, the full continuum of inclusion including community participation, transportation, housing education, and health and function must be addressed.

The ADA is a comprehensive and complex law and not easily understood by the general population including our organization's constituency. Omitting technical assistance on the ADA is a major concern. We believe technical assistance as provided by the DBTACs and ADA Coalitions is, and will continue to be, critical to implementation of the Americans with Disabilities Act.

Therefore, we recommend that NIDRR re-draft the draft Long-Range Plan for Fiscal Years 2010-2014 to more accurately reflect what we believe was Congress' intention when it established the agency. The plan needs to reaffirm NIDRR's obligation to provide technical assistance in the form of information and training activities provided directly to individuals. We also recommend that the revised plan better reflect the objectives and philosophy with those of the new administration.

CONTRIBUTOR: David Stewart
WV ADA Coalition
wvadacoalition@msn.com
(304) 925-8622

DCN: 386

RECEIVED: 3/16/2009

COMMENT: Thank you for the opportunity to comment on NIDRR's Long range Plan.

NIDRR is a unique and important agency for persons with disabilities. Its mission of improving the lives of persons with disabilities and their opportunities for full participation recognizes the impediments, potential and national imperatives of full citizenship. In the past NIDRR's mission and related goals have well-reflected, indeed have substantially contributed to the WHO framework of understanding and responding to disability at the intersection of individual impairments, environmental contexts and personal characteristics. In NIDRR's vision self-determination, environmental accommodation, rehabilitation talent and technology, and social policy have all been important ingredients to supporting persons with disabilities to experience personally satisfying, self-defined levels of participations in the social, cultural and economic life of the community and nation. Only NIDRR among federal agencies has consistently and effectively focused on individuals with disabilities as whole people, not as health care consumers, or subsidized housing users, or long-term service recipients, or person care clients, etc., but as people seeking self-defined qualities of life.

Because NIDRR operates with a broad mandate, but limited budget its Long Range Plan is important vehicle to its focus. Those who care about NIDRR and its mission look at it carefully. The currently proposed Long Range Plan would seem to suggest a shift of emphasis within NIDRR to greater emphasis on employment as the means to "full participation" and improved lives than have the more recent Long Range Plans. Of course, employment is an important means to full participation.

Employment has important economic and social implications for individuals with disabilities. Employment should be a major focus of NIDRR, but in reading the proposed plan one wonders if there is a danger that NIDRR is viewing employment as essentially the equivalent of social participation and good quality of life. The reality of the lives of Americans with disabilities seems more complicated than that. Too many people with disabilities live lives that are segregated and isolated-often still in the very types institutions from which the ADA and Olmstead promised relief. Too many people live lives without personal support or social relationships. Too many people have no choice in the home in which they live or with whom they live. Too many people cannot access their own communities. Too many people have nowhere to go and no way to get there if they did. Too many people live lives governed by policies that promote isolation and policies that force them to live in abject poverty in order to receive the basic health and social assistance on which their very survival depends.

NIDRR has been a leader in recognizing that the goals that our Nation holds for its citizens with disabilities are complex and multi-faceted, and that a one dimensional approach is unlikely to be successful in achieving the outcomes of full participation and improved quality of life. I am hopeful, based on NIDRR's record of leadership that the apparent emphasis of employment in the Long Range Plan does not suggest that NIDRR is drifting away from ICF model and vision for which it has been an effective and valued advocate.

Other than the concern that NIDRR may be drifting toward imbalance in its emphasis on employment, the proposed plan seems comprehensive and offers a good outline of NIDRR's proposed approach. In particular the "Guiding Principles" seem to define a good standard of quality against which NIDRR can continuously review itself. One might hope in particular that NIDRR take particularly seriously the standard of partnership, working more directly and effectively with its constituents in establishing priorities and initiatives. Also one might also hope that NIDRR take seriously the need to work more directly with other Federal agencies as identified in the guiding principles. Disability research and knowledge transfer is dispersed across many Federal agencies and often it is hard to find evidence much, if any, knowledge, much less coordination among them regarding disability research priorities and funding. The Interagency Committee on Disability Research is a showcase for ongoing research but does not seem adequately attentive to the need for documenting and coordinating a national research on disability. With limited national resources and much left to accomplish in fulfilling the promise of full inclusion, commitment to such a role seems badly needed and NIDRR seems the logical organization to lead such an effort. Thank you for the opportunity to review NIDRR's clear and concise proposal for the next five years.

CONTRIBUTOR: K. Charlie Lakin
RTC on Community Living/ICI
lakin001@umn.edu
(612) 624-5005

DCN: 387

RECEIVED: 3/16/2009

COMMENT: In carefully reviewing NIDRR's Proposed Long-Range Plan as outlined in the Federal Register announcement of January 15, 2009 we could not help but notice a move away from the fundamentals to which NIDRR and its establishing legislation had, for some time, a strong commitment. We have always felt that NIDRR's leadership in research direction for people with disabilities has been consistently laudatory and showed great foresight. Thus, our concerns lay with the change in focus proposed in the Plan.

The foundation of NIDRR's support for disability-related research has always been based on an equitable distribution of focus and resources for three primary areas encompassing health and function research, employment-related research, and research related to community participation or as stated in your proposal, research directed toward the full inclusion and integration into society, employment, independent living, family support, and economic self-sufficiency of individuals with disabilities throughout the lifespan. While the heightened focus on supporting research in the area of employment is laudatory, it appears that it will be done so at the expense of many, as of yet, unrealized or uncompleted research developments in the other priorities. There is clearly a need for more research not only on employment, but also on other aspects of community participation as well as on health and function. Some adults with disabilities, particularly those with severe cognitive disabilities or chronic health challenges may not be able to work. Further, as the Federal Register document states, much of the workforce in the United States will be aging and one could argue that the focus on research ought not be on keeping all older persons employable (to the detriment of earned retirement), but gaining more quality of life years. Many people with long- and late-life disabilities are in these same situations and should be able to share in the joys of retirement as can anyone else.

To this end, we fully support NIDRR's historical efforts at underwriting research in a variety of health and function areas and in the mechanisms that enable persons with disabilities to continue to function within and beyond their current capacities, live comfortably within our society, and endeavor to be as independent as possible. Much yet has to be done in this area, as many of NIDRR's RRTCs and RTCs have only begun to contribute to the technological pool and informational stream which collectively and in aggregate will help people with disabilities rise above feeling they are treated as having a second class status. There is still much work to be done exploring unknowns with respect to medical and social factors related to disablement, defining new technologies that help with community participation and prepare people with disabilities to gain skills and maximize their capabilities in pursuit of becoming employable or helping them maintain their employability in these dire economic times.

Thus we urge you to give due consideration to continuing the equitable focus of the various NIDRR legislatively mandated areas of research and development and while keeping employability as a mission and goal, not stress it so it disadvantages support for the other legislatively mandated areas.

CONTRIBUTOR: Charlotte Tate
University of Illinois at Chicago
tate@uic.edu

DCN: 388

RECEIVED: 3/16/2009

COMMENT: I am concerned about the narrow focus on employment issues in the draft long-range plan, and I urge the Assistant Secretary to withdraw the plan as written and initiate creation of a new plan that extends beyond this one area. Better employment opportunities, and better success in the labor force, are important issues for many people with disabilities. A substantial part of my own research focuses on employment, and I believe that much of NIDRR-funded research in this area has the potential to contribute significantly to improving outcomes. But employment is by no means the only issue that people with disabilities face, and a large fraction of people with disabilities—whether children, elderly people, or working-age adults who are either successfully employed and accommodated or unable to consider working for purely health reasons—would not benefit from employment research at all.

Indeed, I believe that other issues trump employment as the most pressing areas for disability research and public policy innovation. Independence is an issue of critical importance to people of all ages with significant disabilities, and NIDRR ought to be devoting a substantial portion of its portfolio to identifying means of preventing institutionalization, of getting people out of institutions, and of keeping people with disabilities living and thriving in their communities. Social integration and participation are also key issues, as well as the related issues of environmental barriers and access to the services, supports, and technology that people need.

I hope the Assistant Secretary will consider broadening the NIDRR long-range plan to include issues of concern to the Independent Living Movement, and to people of all ages with all types of disabilities.

CONTRIBUTOR: H. Stephen Kaye, Ph.D.
University of California, San Francisco
steve.kaye@ucsf.edu
(415) 502-7266

DCN: 389

RECEIVED: 3/16/2009

COMMENT: The purpose of this letter is to provide comments to the Assistant Secretary for Special Education and Rehabilitation Services regarding the proposed long range plan (FYs 2010-2014) for the National Institute on Disability and Rehabilitation Research (NIDRR).

Since the U.S. Congress established NIDRR in 1978, it has served as the flagship federal agency on disability and rehabilitation research. NIDRR is a mission-oriented agency—its mission is to explore the interaction of individual characteristics and environmental factors and their effects on the participation of individuals with disabilities of all ages in the home, community, school, and workplace.

In the two previous long-range plans covering FY1999 through the present, NIDRR has recognized that in order to carry out its mission, research and development activities must focus on three major life domains:

- Employment,
- Participation and community living, and
- Health and function (including medical rehabilitation interventions to improve function and health status research to improve overall health and wellness of people with disabilities).

In addition, NIDRR has recognized the need to focus on technology for access and function and disability demographics.

On January 15, 2009, the acting Assistant Secretary for Special Education and Rehabilitative Services published a notice in the Federal Register proposing a long range plan for NIDRR for Fiscal Years 2010-2014. The proposed plan specifies that the "improvement of employment outcomes [will be] the focus of its long range plan for FYs 2010-2014." [74 FR at page 2566] In this new proposal, the focus of research and development activities relating to the life domains of participation and community living and health and function have been relegated to a less prominent status, thereby undermining NIDRR's mission to improve participation of persons with disabilities of all ages in the home, community, school, as well as the workplace.

Although we strongly support research and development activities that focus on employment, we believe that there is a continuing need for NIDRR to recognize and focus on health and function as a distinct life domain. Without health and function, individuals with disabilities are less likely to participate in the community and employment. In the past NIDRR has appropriately recognized that there are many instances in which meaningful improvements in health and function may not always translate directly into changes in vocational outcomes. If NIDRR is to accomplish its congressionally-mandated mission, it must continue its longstanding policy of focusing research and development activities in all major life domains, including participation and community living, health and function, as well as employment.

Infants, children, adolescents, and the elderly, as well as working age Americans with disabilities must benefit from the research and development activities conducted NIDRR. NIDRR should reaffirm its longstanding recognition that rehabilitation includes ongoing management of chronic conditions as people move through their lives. NIDRR must maintain a broad portfolio of disability and rehabilitation research that, in the words of the Rehabilitation Act, is designed to "maximize the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities of all ages."

In order to fully and faithfully carry out NIDRR's mission, we urge the new Assistant Secretary for Special Education and Rehabilitative Services and the Director of NIDRR to restore the broad focus of NIDRR's research and development activities by recognizing the critical importance of all major life domains affecting persons with disabilities, to include participation and community living, health and function, as well as employment.

Thank you for this opportunity to submit comments to NIDRR's next Long Range Plan.

CONTRIBUTOR: Gale Whiteneck, Ph.D.
Craig Hospital
nkamenoff@craighospital.org
(303) 789-8202
Co-signing:
Dan Lammertse, Medical Director of Research,
Cynthia Harrison-Felix, Assistant Director of Research
Susan Charlifue, Co-Director, Rocky Mountain Regional Spinal Injury System
Amit Jha, Research Physician
Cynthia Dahlberg, Co-Director, Rocky Mountain Regional Brain Injury System
David Ripley, Medical Director, Rocky Mountain Regional Brain Injury System

DCN: 390

RECEIVED: 3/16/2009

COMMENT: I am writing to make comment on the proposed long-range plan for fiscal years 20102014 for the National Institute on Disability and Rehabilitation Research (NIDRR). Thank you for the opportunity to do so.

I was especially interested to read your background information presented in the January 15, 2009 Federal Register relevant to American Indians. It noted that 2006 census data indicated that 32.4% of American Indians with disabilities nationally were unemployed. This statistic, while alarming to us, is not surprising since we battle to overcome this problem on a daily basis here on the Mississippi Band of Choctaw Indians' reservation.

This disparity in employment for American Indians with disabilities has been the local focus of the Mississippi Band of Choctaw Indians since 1987 when the Tribe first began operation of a Vocational Rehabilitation Services Agency. Since that time, the Tribe has worked diligently to close that gap between employment statistics of disabled and nondisabled Tribal members. Later, in 2003, through a discretionary grant, the Tribe began to operate an Office for Independent Living Services which has worked to serve our Tribal members with significant disabilities to live independently in their community and some to move into employment endeavors.

When reading your goals, objectives and strategies, I was excited to learn of some of the aspirations for the coming years. However, I wanted to present my hope that you will target some of your research activities specifically to American Indians with disabilities. We have learned over time in the operation of the Vocational Rehabilitation Services Agency as well as the Office for Independent Living Services that sometimes, strategies developed for the majority culture do not translate into effective strategies for American Indians due to cultural, language, and geographical considerations.

We are in sincere hopes that you will fund certain projects to focus distinctly on American Indians with disabilities. It has been established long ago that American Indians just don't access state provided services for disability service needs. This is in spite of the fact that, at least in our state, that the Designated State Unit, Statewide Independent Living Council, and Center for Independent Living all have demonstrated willingness to provide disability-related services to American Indians with disabilities.

We are especially interested in projects that focus specifically on Independent Living services for American Indians with significant disabilities. You see, five years ago, the Rehabilitation Services Administration funded the Mississippi Band of Choctaw Indians to operate an agency to provide Independent Living Services for our members with significant disabilities. An agency structure was developed in these five years that meet the cultural, language, and geographical needs of the Choctaw people, while effectively meeting their Independent Living Services needs. This system has been created with very little federal funding; and has been developed in a way that utilizes existing Tribal services, some not directly focused on disability issues, to best serve Tribal members who have significant disabilities in a cost-effective way. This funding is set to end September 30, 2009 with no funding stream open at the present time for us even to apply for continuation. This developed system will be, in essence, lost due to non-continuation of funding. This type of situation - where something is started, but not continued - should be a real focus of NIDRR. It would seem cost effective to study effective practices and attempt replication versus funding start-ups that simply go away after the funding ends.

Again, thank you for the opportunity to make comments on your proposed long-range plan. We are excited to see the outcomes and truly hope to see that you will earmark certain projects to deal specifically with American Indian disability issues.

CONTRIBUTOR: Beasley Denson
Office for Independent Living Services
Mississippi Band of Choctaw Indians
PO Box 6010, Choctaw, MS 39350
(601) 650-7333

DCN: 391

RECEIVED: 3/11/2009

COMMENT: The DBTAC-ADA Centers wish to comment on the NIDRR Long Range Plan. Upon review of the plan, we would like to discuss issues with the LRP that fall into three categories—omission of ADA technical assistance activities, focus of the plan, and alignment with the new administration's disability agenda.

1. Omission of Technical Assistance Activities through Direct Services to Consumers

The LRP does not acknowledge NIDRR's responsibilities to provide information, training and technical assistance on the Americans with Disabilities Act and also provides no direction regarding

1. how its technical assistance project (DBTAC-ADA Centers) will be managed
2. necessary resources will be allocated and
3. activities will be coordinated with other federal efforts on ADA implementation. However, NIDRR is specifically charged with carrying out these activities.

According to 29USC76, NIDRR and the secretary are charged with 2: (11) coordinating activities with the Attorney General regarding the provision of information, training, or technical assistance regarding the Americans with Disabilities Act of 1990 (42 U.S.C.12101 et seq.) to ensure consistency with the plan for technical assistance required under section 506 of such Act (42 U.S.C. 12206)

<http://law.justia.com/us/codes/title29/29usc762.html>

NIDRR's omission in its LRP of technical assistance on the ADA is a major concern for the DBTAC-ADA Centers, as we believe technical assistance is, and will continue to be, critical to implementation of the Americans with Disabilities Act. The ADA is complex legislation that is not easily understood by the general population. The ADA establishes the necessary minimum standards for many types of environments including work, state and local government and public accommodations. It is critical piece of civil rights legislation that continues to be recognized as a model in the rest of the world. However, the ADA was written by lawyers and needs to be explained to US citizens. Congress recognized this in the absolute requirement of Title V of the ADA that executive branch agencies develop plans to assist entities covered by the law in understanding ADA rights and responsibilities through the provision of information and technical assistance about compliance strategies (PL 101-336, 1990). Many ADA terms and requirements are not easily understood by the general population. Definition of disability; reasonable accommodation; undue hardship; reasonable modification of policies, practices and procedures; readily achievable barrier removal; effective communication; undue burden are just a few of the ADA terms and requirements that consumers need technical assistance to understand. Often, guidelines for complying with ADA regulations require a certain level of expertise to implement, such as providing accessible information technology or accessible facilities. Direct service delivery is vital to ensure this level of expertise is available to the public. The questions the DBTAC-ADA Centers receive on the ADA technical assistance phone line (1-800-949-4232) are more complex and novel than at any time in the past 18 years requiring more research and discussion on the part of technical assistance staff. In addition, keeping the public apprised of court decisions relative to the ADA has grown in complexity and importance as well. With the advent of ADA Amendments Act and other major changes to ADA regulations, an explanation of the ADA to the general public will be more critical and intricate for those who need to trigger their rights and others needing to fulfill their obligations.

The DBTAC-ADA Centers also believe it is critical that any technical assistance delivery system be comprehensive, covering all areas effected by the ADA including education, housing, transportation, employment, community access, civic participation, access to healthcare, recreation, and information technology. The ADA, as a unique civil rights law, must be implemented in its entirety and technical assistance efforts to assist in this implementation must also cover the ADA in its entirety.

2. Narrow Focus

The Long Range Plan (LRP) focuses on employment, omitting, if not ignoring, the importance of all areas that affect disability. NIDRR's mission "to support research and related activities to generate new knowledge and promote its effective use to improve the lives of people with disabilities and their opportunities for full participation in society" is not reflected in the current LRP. By focusing the LRP exclusively on employment, NIDRR erroneously narrows its scope considerably and neglects the concept of "full participation". For people with disabilities to achieve full participation in society, the full

continuum of inclusion including community participation, transportation, housing education, and health and function must be addressed. This full continuum also includes addressing the needs of people with disabilities across their life-spans. By focusing only on employment issues, the LRP does not address areas relevant to the needs of children and seniors with disabilities. Improving health and function and community participation for both of these groups should be critical goals contained in NIDRR's long-range plan. The DBTACs contend that not only does the narrow scope of the LRP ignore NIDRR's mission, but that community participation, transportation, housing, employment, education, and health and function are interrelated. Narrowly focus on only one area limits both the effectiveness of NIDRR's activities and the goal of positive outcomes in employment. It is a fact in everyone's life that one's education, socioeconomic status, health, transportation and access to public accommodations interplay with our ability to work. For people with disabilities, it is even more significant. Therefore, we believe NIDRR must give each arena of life equal weight in the LRP. We strongly recommend NIDRR to expand its emphasis on employment to reflect that employment depends on the rest of life: education, access to public accommodations, health, transportation and community living and the changing trends in the nature and distribution of disability as further described.

Youth

Students in K-12 with IEP's range from 13% -25% from school building to school building and across school districts. Of this share, 44% report learning disabilities, 16% language disabilities, 9% intellectual disabilities, and 7% emotional disabilities (U.S. DoE, 2001-2002, IDEA). Most students with disabilities enroll in public 2-year community colleges. Generally, when these students enter higher education, the share of self-reporting a disability is 11.4%. However, the reality is that for many reasons, most students are not reporting a disability at the post secondary level. Not only that, we don't know what happens to these students. There is a strong correlation between educational attainment and employment. Now, more than ever, students with disabilities are enrolling in colleges, but what happens to them? Do they stay in school? Graduate? Dropout? Get jobs? Through our current research activities, we will find out the answers these questions.

Disability and Poverty

Disability and Poverty Research shows a strong connection between poverty, functional limitations and disabling environments. Some factors related to poverty are poor nutrition, poor medical care, lack of education, illiteracy, low birth weight babies, substance abuse and violence. Maine has the oldest population in the US. Maine is also the poorest and has the lowest educational attainment of all the New England states. It is no wonder that Maine has the highest incidence of disabilities of all the New England states (Center for Labor Market Studies, 2008).

Working Age Population

In the working age population, arthritis, back problems, heart disease and respiratory problems are the leading causes of disabilities. The labor force continues to age with an annual growth rate of the 55-years-and-older group projected to be nearly four times that of the overall labor force (Center for Labor Market Studies, 2008). The reality of the older worker, and their increasing incidence of disabilities, indicates a critical need for accommodations and accessible technology training for both workers and employers in order to enhance job performance and improve job retention.

Returning Veterans from Iraq and Afghanistan Conflicts

Veterans with disabilities are re-entering the workforce, educational institutions, and re-engaging in their communities. These veterans deserve to participate and be integrated into all areas of American society. Issues of particular relevance to this group are physical access to the built environment and accommodating head injuries in work and educational settings.

The Uncounted People with Disabilities

Add to this, the emergence of 'new disabilities', such as: AIDS/HIV, Attention Deficit Hyperactivity Disorder (ADHD), violence-induced neurological damage, repetitive motion syndrome, brain-based disabilities, diabetes, cancer, heart disease, chronic fatigue syndrome, drug addiction and environmental illnesses. This group outnumbers a traditional disability population using wheelchairs, white canes and sign language. But who with diabetes or cancer would self-report themselves as having a disability? What is the benefit of reporting a disability on a government census? Whether on a government census, in college, or at work, there is a large share of people with disabilities that will

never be counted.

Aging and Disability

All of this, including the well documented prevalence of disabilities in the aging population 65 and older should catapult us into a new way of thinking. From all estimates, we know that disability has become a common American experience.

3. Misalignment with Administration's Disability Agenda

The DBTAC-ADA Centers have strong concerns regarding the inconsistency between the LRP and the new administration's disability agenda. HYPERLINK "<http://www.whitehouse.gov/agenda/disabilities/>" <http://www.whitehouse.gov/agenda/disabilities/> President Obama's 4-point disability agenda outlines a comprehensive approach to improve the lives of individuals with disabilities. The plan outlines the need for efforts designed to:

1. improve educational opportunities;
- 2.. restore the ADA;
3. promote health and mental health care;
4. increase community living opportunities for individuals with disabilities including improved employment outcomes

NIDRR's current Long Range Plan focuses on only one area of participation - employment, and does not acknowledge the importance of compliance with existing laws to improve overall quality of life for people with disabilities. The new administration's plan specifically states that full implementation of IDEA, the ADA, and the Community Choice Act, as well as better access to health care is the foundation of its disability policy. The LRP fails to address any part of the administration's disability agenda. The DBTAC-ADA Centers believe a unified commitment from all agencies to carry out an overall disability agenda as directed by the current administration is the most effective way to improve the quality of life for people with disabilities.

Summary

In conclusion, the DBTAC-ADA Centers recommend NIDRR to withdraw the LRP and make revisions to more accurately reflect Congress' intention when it established the agency. This re-drafted LRP should more closely reflect a disability and rehabilitation research agenda designed to enhance self-determination and participation in the home, community, and workplace through research, technical assistance, training, and dissemination activities. The LRP must reaffirm NIDRR's obligation to provide technical assistance in the form of information and training activities provided directly to consumers. We also recommend that the revised LRP better align its goals, objectives, and philosophy with those of the new administration.

Respectfully submitted by the DBTAC-ADA Center Network

CONTRIBUTORS: Oce Harrison, DBTAC-New England ADA Center
 Susanne Bruyere, DBTAC-Northeast ADA Center
 Marian Vessels, DBTAC-Mid Atlantic ADA Center
 Shelley Kaplan ,DBTAC-Southeast ADA Center
 Robin Jones, DBTAC-Great Lakes ADA Center
 Wendy Wilkerson, DBTAC-Southwest ADA Center
 Jim de Jong, DBTAC-Great Plains ADA Center
 Jana Copeland, DBTAC-Rocky Mountain ADA Center
 Erica Jones, DBTAC-Pacific ADA Center
 Don Brandon, DBTAC-Northwest ADA Center

DCN: 392

RECEIVED: 3/15/2009

COMMENT: NIDRR's Proposed Long-Range Plan as outlined in the Federal Register announcement of January 15, 2009 has a heavy emphasis on employment. Employment has clearly been a major focus of NIDRR since its inception as a federal agency after passage of the Rehab Act of 1973 and should remain so. However, as the agency has matured, it has properly recognized the need for a broader focus that places employment within the overall context of the lives of people with disabilities. Accordingly, NIDRR's mission currently embraces a balance between the major life domains of employment, community participation and health and function. While these latter two domains remain in the proposed long range plan, their roles appear to be substantially diminished when compared to NIDRR's previous long range plan (2005-2009). We strongly urge you to restore this balance in the proposed long-range plan.

The balance of these three major domains is not simply an idealized goal for a harmonious life. Wellness research has consistently confirmed the multi-dimensional nature of quality of life and that deficiencies in one domain invariably impact the others. Our work has focused on health and function. Research has clearly shown that social participation and physical activity are equally important dimensions of good health and well being. National data sets have provided evidence that there are substantial health disparities between people with and without disabilities that often impact and limit their employment opportunities. People with disabilities are at high risk for developing one or more secondary conditions (IOM Report, *The Future of Disability in America*, 2007), and this additional burden increases the difficulty that people with disabilities have in sustaining their participation in the labor force. Specific secondary conditions such as pain, fatigue, sleep problems and depression have been cited as reasons people with disabilities are not able to obtain or keep jobs. The physical and emotional impacts of secondary conditions may force individuals with a physical disability to retire early, reduce employment time, or take a greater number of sick days. There is growing evidence that many of these secondary conditions can be prevented or ameliorated through effective health promotion programming.

The much publicized alarm at the increasing rate of obesity in America is a particular concern for people with disabilities. Two population-based studies reported on the prevalence of obesity among adults with disabilities. Weil et al. (Weil et al., 2002) pooled data from the 1994-1995 National Health Interview Survey (NHIS), the 1994-1995 Disability Supplement (NHIS-D), and the 1995 *Healthy People* 2000 Supplement. The rate of obesity among adults with disabilities was found to be 66% higher compared to people without disabilities. Those with severe lower extremity mobility difficulties had the highest obesity rates, were less likely to attempt weight loss and were less frequently counseled by their physicians about weight loss. They also had higher percentages for poverty (27% lived in poverty) and an inability to work (74% higher rate of non-employment) compared to the non-disabled sample. Children and adolescents with disabilities also have a significantly higher prevalence of obesity compared to their non-disabled peers (Rimmer, et al., *Journal of Adolescent Health*, 41, 224-229), which leads to a greater number of obesity-related secondary conditions (e.g., fatigue, pain, deconditioning, social isolation, difficulty performing activities of daily living) and significant personal and economic hardship on the child and family.

The development of innovative strategies for improving health, preventing secondary conditions associated with a disabling condition, and adequately preparing individuals with disabilities to understand and manage their own health must continue to be high priorities in NIDRR's long range plan for 2010-2014. The National Institutes of Health direct the vast majority of their resources toward basic research targeting cures for existing diseases and disorders. The Centers for Disease Control and Prevention focuses primarily on population-based health promotion planning through epidemiology and surveillance. NIDRR is currently the primary agency funding research and development of programs that can directly impact the health and wellness of youth and adults with disabilities. We strongly encourage the administration to reconsider its priorities in the 2010-2014 long range plan and restore a better balance among its three current domains—employment, community participation and health and function.

CONTRIBUTOR: James H. Rimmer, Ph.D.
Professor, Department of Disability and Human Development
Adjunct Professor, Department Kinesiology and Nutrition and Bioengineering
Adjunct Professor, Department of Physical Medicine and Rehabilitation, Northwestern University
William J. Schiller, Ph.D.
Assistant Professor, Department of Disability and Human Development
