

RFI: Beach Center on Disability, The University of Kansas

Background:

The Beach Center on Disability is a federally funded research and training center committed to making significant and sustained enhancements of the quality of life of individuals and families affected by intellectual, developmental, emotional-behavioral, and sensory disabilities through research and its application to the policies and service-delivery systems affecting them.

The Center's investigators receive or have received peer-reviewed competitively awarded federal funds from the National Institutes of Health (both Child Health and Human Development and Human Genome Project), Department of Education (Institute for Education Science, National Institute on Disability and Rehabilitation Research, and Office of Special Education and Rehabilitation Services), Department of Defense (Office of Community Services for Individuals with Special Needs), and Department of Health and Human Services (Administration on Developmental Disabilities). Its investigators consist or have consisted of individuals with terminal or next-to-terminal degrees in special education, developmental psychology, law, social welfare, and public health.

We are the co-founders and co-directors of the Beach Center and have our terminal degrees (Ann Turnbull, Ed.D; H. Rutherford Turnbull, LL.M.). We established the Center in 1988 with funding from the Department of Education, supplemented then and later by federal, state, and private funding.

We incorporate by reference the responses of the Provost, The University of Kansas, and we particularize our responses by linking them directly to our Center.

Question 1

Part a. We concur with the University of Kansas Provost's statements that (a) research articles must be made permanently and publicly available and (b) availability of research benefits several interested groups of research stakeholders (beneficiaries). These beneficiaries are (a) members of the research community themselves; (b) individuals with disabilities and their families; (c) professionals who provide services to those individuals and their families; and (d) federal and state policy-makers. We concur with the Provost for two reasons.

First, given our Center's mission, we are particularly determined to assure that our research is available, accessible, and appropriate to the four groups of research-stakeholders.

Second, our field entails a consistent and often unbroken chain between invention, innovation, intervention, and integration (the 4-I cycle). Basic research in disabilities constitutes invention; it creates data that are grounded on theories/hypotheses about human development and public services. Invention spurs innovation by stimulating new understandings and potential approaches to enhancing the quality of life of individuals affected by disability. These

understandings and approaches in turn lead to interventions through service-delivery that is authorized and funded by evidence-based policy. Finally, the interventions enhance the legal and actual opportunities of individuals with disabilities to participate in and contribute to the mainstreams of their communities of choice.

Part b. We concur with the University of Kansas' Provost's statement that public access to research creates greater opportunities for serendipitous contributions in research. But we add that such access also creates deliberate (as distinguished from serendipitous) opportunities related to policy and practice (the 4-I cycle, mentioned above).

When the 4-I cycle exists, research feeds on itself. Researchers learn from service-delivery professionals and individuals/families how relevant their research is to quality of life. That reciprocal research-to-practice model cannot exist unless researchers and practitioners, together with individuals and families, have easy access to new research results. In turn, policy makers in turn learn from individuals, their families, service-delivery professionals, and researchers alike "what works" and, thus fortified by evidence, are able to craft policies that authorize and appropriate funds for services and further research.

This interactivity solves or tends to solve some questions addressed by the research community, even as it unveils other questions for research. More than that, however, the interconnectivity creates new services within the nation's economy. For example, special education is a human service that has grown significantly over the last 30 years as a direct result of research that became the basis for policy and practice. There are numerous examples of the power of research to affect policy and practice; among them are research on educability, language acquisition, assistive technology, behavior modification and especially non-aversive, positive behavior intervention and support, and integration in schools and communities. Similar effects of research on policy and practice obtain with respect to rehabilitation, housing, transportation, employment, and homeland security.

Part c. Part b, above, describes the benefits of open-access policies. The costs of open access are relatively minor and consist largely of those that the research community meet when converting research findings into language that lay persons and policy leaders can readily use.

Part d. We concur with the University of Kansas' Provost's statement that immediate public access with re-use rights is essential to contribute to economic growth, augment the research enterprise, and enhance policy and practice. The longer the delay in the 4-I cycle (mentioned above), the lower the likelihood that economic growth and enhanced quality of life will obtain; instead, they may be impeded by the continuation of policies and practices that are deliberately segregating and demeaning, and often cost more than research-based practices.

When too-costly and too-segregating practices continue in spite of the existence of contrary data, scarce human-resources funding is wasted, economic growth in cost-effective services is delayed, researchers seeking to bolster their peers' more cost-effective and beneficial research are blunted in their efforts, and policy improvement is thwarted.

The continued use of institutional models – involuntary placement of individuals with disabilities into large, expensive, and generally ineffective institutions – proves the validity of these assertions. Likewise, the continued use of seclusion, restraint, and aversive interventions to shape the behavior of individuals with challenging behaviors further evidences waste of fiscal resources when, instead, less costly and more intervention-effective practices, grounded solidly in research, exist but may not be as accessible as they should be.

Question 2

We concur with the University of Kansas' Provost's answer to Question 2. We add that the data we and our colleagues develop and publish have a single purpose. It is to make significant and sustainable enhancements in the quality of life of individuals and families affected by disability.

Although our research undoubtedly adds to our individual standing (and our university's standing) in the research community, our research's real benefit is far beyond reputational. Our research asks questions and proposes answers; these answers in turn generate potential solutions (the 4-I cycle). Consistent with the Beach Center's mission, the greater interest to our intellectual property lies with individuals, families, policy makers, and practitioners, not with us and our publishers.

Question 3

We lack sufficient knowledge to answer Question 3 and therefore defer to the University of Kansas Provost's answer.

Question 4

We repeat our answer to Question 3.

Question 5

We adopt as our own the answer of the University of Kansas Provost.

Question 6

We adopt as our own the answer of the University of Kansas' Provost.

We add, however, that the end-beneficiaries of research – individuals and families, and, before them, service-delivery professionals and policy makers – are challenged by information-overload. When they seek evidence-based answers to real-world, practice-related inquiries, they may as well submit themselves to a fire-hydrant flow of data when in fact all they want is a carefully modulated, highly targeted drip of data.

Knowledge translation requires the research community to invent/create, then synthesize, and finally assist in developing research-based policies, procedures, practices, and personnel to enhance people's quality of life. Granted that knowledge translation usually is not the principal concern of the research community; it is, nevertheless, an element of the ethical obligation of that community to answer the "so what" question: So, now that there are data suggesting solutions in policy and practice, what may be done to make those data available to individuals, families, practitioners, and policy makers?

It seems utterly logical for federal agencies that sponsor research to require and provide funds for knowledge translation.

Question 7

It is essential to make available to the public book chapters, conference proceedings, technical reports, "white papers," and expert-witness testimony before Congress. Often these publications collect, analyze, synthesize, and thereby make more accessible to the beneficiaries of research the many peer-reviewed published articles that the research community produces. They are as useful, and sometimes they are more useful, to research beneficiaries than peer-reviewed articles because they present in a nutshell what researchers present in a forest of peer-reviewed journals.

Question 8

We agree with and adopt the University of Kansas' Provost's answer to this question.

Other Items for the Task Force

There are two other items for the Task Force to consider.

The first relates to knowledge translation, which we discussed above.

The second relates to accessibility of published research results and data to individuals who have visual impairments. Given that the data with which the Task Force is concerned are "published" in journals or other formats, these data regularly are inaccessible to visually limited individuals. They are, then, not truly published – not truly made public. Instead, they are quasi-published – made public in a way that only some people can access them. Visually limited individuals are researchers themselves; more often, they are individuals with disabilities or their family members, service providers, and policy makers.

The Task Force should address both knowledge translation and research accessibility.

Respectfully submitted,

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*U:Open Access RFI Whit House Office of Science and Technology Practice
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