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June 12, 1986

TO: Members of the Advisory Committee
Center for Disability Policy

FROM: Monroe Berkowitz

This is a follow-up to our last communication enclosing the minutes of our February 27, 1986 meeting at George Washington University.

We have been busy developing a research agenda, exploring the feasibility of a center and working on examples of research products. We also have been engaged in a related activity which gives rise to this memorandum.

NIHR announced that they intend to fund a Policy Research Utilization Center. The functions of the center will be to summarize, evaluate and disseminate research in the designated priority areas which include the economics of disability, work disincentives, habilitation of children and community based care. The proposed center emphasizes utilization and dissemination of existing research rather than the generation of new research. We thought it was at least a part of what we had in mind and decided to apply for it.

Since the mandated priority areas included habilitation of children, we sought the collaboration of the University Affiliated Facility (UAF) at the Rutgers Medical School and the cooperation of Dr. Elizabeth M. Boggs who is a member of our Advisory Committee. Because of the need to identify research, we asked the National Rehabilitation Information System (NARIC) for their cooperation. Both the UAF and NARIC were more than willing to join with us. Also, cooperating in the project will be Rehabilitation International, Dale Hanks of the Virginia Department of Rehabilitative Services, Stanley Portny, and Ethan Ellis, who helped arrange our February meeting.

For those members of the committee who have not already seen it, I am enclosing a copy of our proposal to NIHR. This copy does not include the letters of support or the resumes. We also included in our proposal the minutes of our February 27, meeting.

We will keep you informed as to the response to the proposal and any future developments.

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Encl

POLICY RESEARCH UTILIZATION CENTER

Grant Application Submitted to the National Institute of Handicapped Research, Office of Special Education and Rehabilitation Services, U. S. Department of Education, Washington, DC, by Monroe Berkowitz, Bureau of Economic Research, Rutgers, The State University of New Jersey, New Brunswick, NJ

June, 1986

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POLICY RESEARCH UTILIZATION CENTER

Application submitted by
Monroe Berkowitz
Bureau of Economic Research
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1. Importance of the Problem

This is a proposal in response to the announced priority for the establishment of a disability policy research utilization center. In accordance with the announcement, the center will be concerned with research related to policies on rehabilitation and employment of disabled persons, especially those most severely disabled. Absolute priority will be given to the following subject areas:

1. Economics of disability
2. Work disincentives
3. Community-based care
4. Habilitation of handicapped children
5. The training and deployment of professionals in rehabilitation-related disciplines

We have assembled a team with expertise in each of these areas. The first two of these areas--Economics of Disability and Work Disincentives--are ones in which the Disability and Health Economics Section of the Rutgers Bureau of Economic Research has had long experience. A pioneering work in this area, Public Policy Toward Disability, was published in 1976.[1] A new volume, Disability and the Labor Market: Economic Problems, Policies and Programs, has

[1] Monroe Berkowitz, William G. Johnson, and Edward H. Murphy, Public Policy Toward Disability (N.Y: Praeger Publishers, 1976).

been accepted for publication.[2]

Responsibility for Community-Based Care and Habilitation of Handicapped Children will be shared. Elizabeth M. Boggs, a nationally known leader in the field of developmental disabilities, will play a prominent role. The Bureau of Economic Research will also be working in collaboration with the University Affiliated Facility (UAF) of the Rutgers Medical School of the University of Medicine and Dentistry of the State of New Jersey (UMDNJ). Both Dr. Boggs and UAF will also cooperate in the area of the Training and the Deployment of Professionals in Rehabilitation-Related Disciplines.

Ethan Ellis, Staff Director of the New Jersey Governor's Task Force on Services to Disabled Persons and a leading disability rights advocate, will be responsible for our outreach functions. Mr. Ellis has been aiding the Bureau in the discharge of its responsibilities under a current grant from the National Institute of Handicapped Research (NIHR) to investigate the "Feasibility of Establishing a Center for Disability Policy."[3] Also joining us in this application are Dale Hanks, Director of Planning and Evaluation of the Virginia Department of Rehabilitative Services, and Stanley Portny, President of Stanley Portny and Associates, Inc. (SEPA) and formerly Director of Evaluation for the Rehabilitation Services Administration. The Virginia department, SEPA and the Rutgers Bureau are collaborating on a project, "Enhancing the Understanding of the Economics of Disability,"[4] as well as the current feasibility study.

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[2] This volume, edited by Monroe Berkowitz and M. Anne Hill, will be published by the ILR Press, Cornell University, in the fall of 1986. It consists of ten essays based on presentations made at the Economics of Disability meeting held in Washington, D.C. on April 9 and 10, 1985.

[3] Grant No. G008535170. The award runs from September 30, 1985 until June 28, 1986.

[4] NIHR Grant No. 133AH30005.

The National Rehabilitation Information Center (NARIC) will be an integral part of the team. Their responsibilities will lie in the identification and dissemination of research. They will also disseminate the publications of the center and assist in the development of a directory of agencies and organizations active in the area of disability policy research.

Lastly, Rehabilitation International, an organization which facilitates the work of national rehabilitation organizations throughout the world, will aid us in the coordination of some of the foreign-based research in the selected areas. The Rutgers Bureau has worked with RI on several projects in the area of disability policy.

We have assembled an experienced multidisciplinary team with strengths in the targeted areas. The team will cooperate in the discharge of the specified functions. For each of the five subject areas, these functions are:

1. Identification of research with policy implications
2. Evaluation of such research
3. Summarization of such research
4. Dissemination of such research
5. Development of a directory of agencies and organization active in the area of disability policy research.
6. Identification of gaps in policy research in areas reviewed for the study.

It will be the central task of the center to make valid research results accessible to policy makers and administrators in timely fashion and in useable form. Research utilization and dissemination activities are traditional in vocational rehabilitation agencies. In 1966, Mary Switzer, then Commissioner of the Vocational Rehabilitation Administration, appointed a task force on

research utilization.[5] The findings of this group led to the creation of a research utilization function in rehabilitation at the federal level and the establishment of a national Research Utilization Specialist (RUS) demonstration program. RUS programs were funded in nine states. The methods of operation and the objectives differed across these states but, for the most part, the purpose of the RUS was to bring research to the attention of the state agencies so as to improve the delivery of services. Changing established practices proved to be difficult, but the RUS programs left their impact on the agencies. A recent check of the nine state agencies revealed that none of them has retained the RUS, but several of the functions remain. In general, NIHR has encouraged research utilization and dissemination by requiring such activities as part of all research grants and by building these activities into the programs of all Research and Training Centers. NIHR and RSA also support the dissemination of research findings through the publication of Rehab Brief and Rehabilitation Research Review.

The disability policy center as we envision it would be a logical outgrowth of Mary Switzer's basic ideas in 1966 about the necessity of some method of disseminating and utilizing research findings. But nearly a quarter of a century has passed and much has changed. Disability costs have exploded, and new groups of handicapped persons, hitherto neglected, have come to the public's attention. In line with the consumer movement in society as a whole, disabled persons have assumed an increasingly active role in the design and development of programs which will serve their needs. Disincentives issues have become a new focus of

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[5] The history and background of the research utilization efforts is taken from Edward Glaser and Associates, "Evaluation of the National Research Utilitzation Specialist Demonstration Program, 1969-1974" (Contract No. SRS-72-41, November, 1974.)

concern, as researchers investigate the relationship between what is done in the benefit system and what is done in the habilitation and rehabilitation fields. It is no longer simply a matter of fixing the tools we have at our disposal in the rehabilitation field; it may be that we must rethink the basic policies which govern and constrain the actors in the field.

To do so requires that we give greater attention to policy analysis. Policy analysis has emerged as a separate discipline in recent years with the establishment of schools and journals devoted to this area. The move is closely linked to evaluation procedures in the public sector designed to provide guidance to public officials and administrators as to the optimal allocation of funds among competing projects. The disability community has felt the effect of these trends but it has hardly been a pioneer in the field of policy research. Disability policy has been driven, at times, by administrative problems in one or the other of the benefit or service programs, by budgetary crises which threaten funding of programs, and by the appeals and demands of consumer groups. As with any other public policy matter, disability policies are not formulated in a vacuum but are influenced by events in the society at large.

In spite of excellent efforts on the part of the National Council on the Handicapped, NIHR and other groups and agencies, it has proven difficult to focus sustained public attention on disability issues per se. There are many reasons for this regrettable state of affairs. On the most basic level, we can point to the considerable confusion surrounding the exact definition of a disabled person. In addition, there is little agreement as to the overall costs of disability, and no consensus as to the efficacy of various ways and means to prevent disability and to minimize its impact. Policies are adopted or rejected as political consensus forms but too often without much in the way of sound

basic policy research.

We are convinced that an adequate research base relating to policy matters would be helpful, but we are not so naive as to believe that it will solve all problems. The political process is directed by many forces; results from the finest research projects constitute only one input into the decision-making process, and that is the way it should be in a democracy. The findings of any one study or even a group of studies seldom have a direct impact on basic legislative or administrative decisions. These decisions stem from habits of thought that are based on what may be termed the conventional wisdom or the prevailing paradigms, and perhaps only the dissemination of accumulated results in a favorable environment can bring about change.

It is this last possibility that opens up a role for a policy research utilization center of the kind we are proposing. The center would enable us to begin taking stock of where we are in the policy research area--to test what is useful and what is not, what is sound and what is not. It would serve the functions of collecting and disseminating research, but more importantly, it would establish a structure for evaluating research and for discerning the applicability and relevance of research findings to policy issues. Only in this way can we be assured that research endeavors will have a positive impact on the lives of disabled persons. It is our hope that the center's activities will eventually help to reshape the customary ways of thinking about, and acting upon, the problem of disability.

2. Dissemination and Utilization

A. Dissemination Activities in Current Bureau Projects

We recognize the importance of publicizing the activities of the center and disseminating its products widely, and we have the benefit of considerable experience in this regard. We intend to pursue the same type of dissemination activities that we have used in other Bureau projects. For example, in one of the projects where we are cooperating with the Virginia Department of Rehabilitative Services and Stanley E. Portny and Associates, Inc., we have undertaken the following activities:

1. Periodic meetings with rehabilitation counselors in the three states where our research activities are taking place--Virginia, Texas and California.

2. The publication of a newsletter, "Update on the Economics of Disability," which contains news items and research results in this broad area of economics as well as news of specific project activities.

3. The publication of some of the research results of the project in two articles which will appear in rehabilitation journals in the fall of 1986.[6]

4. Presentations at the following meetings and conferences in the last two years:

   A. Council of State Administrators of Vocational Rehabilitation.

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[6] David Dean and Robert Dolan, "Issues in the Economic Evaluation of the Vocational Rehabilitation Program," Journal of Rehabilitation (forthcoming, Fall 1986); and David Dean and Robert Dolan, "Towards an Improved Methodology for Estimating Benefits of the Rehabilitation Program," Rehabilitation Counseling Bulletin (forthcoming, Fall 1986).

B. American Association for Public Administration.

C. National Association of Rehabilitation Research and Training Centers.

D. Southern Economic Association.

E. Region III Planning and Evaluation Forum.

F. New Jersey Governor's Committee on the Disabled and Governor's Task Force on Services for Disabled Persons

G. Rehabilitation International Congress, Lisbon, Portugal.

H. Helen Keller Memorial Seminar of the American Foundation on the Blind.

I. Committee on Pain and Chronic Illness Behavior of the National Academy of Sciences, Institute of Medicine.

Although we will seek out new audiences if the policy research center is funded, the range of our dissemination activities would be similar to that illustrated above.

B. Target Audiences

The purposes and the activities of the center should be widely known so that researchers will contribute their work for examination and dissemination and policy makers and administrators will know that they can turn to the center for advice in solving immediate or long-range problems. The products of the center must be targeted to the audience for which they are intended so that maximum use will be made of them.

We intend to bring our analysis to the attention of a variety of groups and organizations. We will define the audience in accordance with the subject area of the research and the particular issues involved. Obviously eligible groups include:

1. Participants in disability and rehabilitation programs and their families. These are the consumers who rightfully influence policy decisions.

2. The staff and administrators of public and private disability-related programs who are concerned with the funding and the performance of their programs.

3. Elected and appointed governmental officials in local, state and federal agencies with concern for related disability policy issues, be they housing, transportation or even general taxation issues.

4. Agencies with responsibility for budgetary oversight.

5. Members of federal interagency bodies such as the Federal Interagency Committee on Developmental Disabilities.

6. Attorneys, judges and administrators of the court systems.

7. Members of legislatures and their staff at all levels of government.

In some fundamental sense, the ultimate target audience is public opinion, for it is among all of us where political consensus forms, where ideas are accepted or rejected and where basic support forms for change.

C. Reaching the Target Audiences

Research products and news of the activities of the center will be sent on a regular basis to persons and organizations on our mailing lists. We have begun the compilation of these lists in our current project, "The Feasibility of Establishing a Center for Disability Policy." Names are entered in the computer with codes to indicate activities or interests. To date we have identified:

1. Consumer and advocate groups.

2. Vocational rehabilitation administrators.

3. Private sector rehabilitation specialists.

4. Disability management administrators.

5. Workers' compensation administrators.

6. State and federal management and budget specialists.

7. Legislative aides.

We intend to refine these lists and to classify the names according to the target areas, i.e. economics of disability, habilitation of children, etc.

D. Presentations at Meetings and Conferences

Reports of our findings will be presented at conferences and meetings. Given the multidisciplinary team we have assembled, we expect to be able to cover not only the rehabilitation conferences but also those meetings concerned with developmental disabilities, advocacy, independent living, public administration, public health, policy analysis, and social insurance, as well as meetings of the several academic disciplines represented in the center. The exact presentations will, of course, depend upon the research products developed. We anticipate that individuals connected with the center will make presentations at the following meetings:

1. The Association for the Severely Handicapped.

2. National Easter Seal Society Meeting.

3. American Congress of Rehabilitation Medicine.

4. Council for Exceptional Children.

5. American Association for Mental Deficiency.

6. National Association of Rehabilitation Research and Training Centers.

7. Council of State Administrators of Vocational Rehabilitation.

8. Paralyzed Veterans of America.

9. American Economics Association.

E. Center Publications

Dissemination involves not only choosing a target audience and devising the best methods of capturing its attention, but also the equally important task of selecting the product to be disseminated. We have several excellent models in the rehabilitation field, including Rehab Brief and the Rehabilitation Research Review. Our concepts of a DISABILITY PRIMER, SINGLE-SUBJECT SUMMARIES and a DISABILITY ENCYCLOPEDIA, described in detail below, are closely related to these models. What will set the center's products apart, however, will be their clear orientation toward policy issues. We will be concerned less with service delivery and counselor-client interaction than with the consequences of serving or not serving particular clients. The center's products will focus on public policy in relation to disability, with rehabilitation assuming its place as one of a number of methods of attacking the problems disabled or handicapped persons face. In the final analysis, the products of the center will be geared toward answering the question, "How can research on policy issues make a difference in the lives of disabled persons?"

3. Project Design

A. Selecting the Issues

The center's eventual goal is the development of an all-embracing unified disability policy which will recognize the relationships among separate parts of the system. But that long-range goal must be approached in a gradual fashion by first dealing with more specific issues.

We expect to work with research in each of the five areas we outlined at the beginning of our proposal. The economics of disability and work incentives will be the responsibility of Monroe Berkowitz assisted by David Dean, and the areas of habilitation of children and community based care will be handled by the UAF faculty in consultation with Elizabeth M. Boggs. The deployment of professionals area will be shared. In each of the areas, the basic tasks are to identify, evaluate, summarize and disseminate the research and to identify the gaps in knowledge.

Since each of the priority areas is quite broad, however, it will be necessary to formulate the issues before we explore the available research; it is at this stage, the identification of the issue, where the process should begin.

In our current NIHR innovative grant, "Feasibility of Establishing A Center for Disability Policy," (hereinafter referred to as the feasibility project), we have begun to experiment with ways to identify issues. Our primary objective in these experiments was to identify issues in which new research might be done, but much the same process could be used to identify the policy issues relating to existing research.

Our method was to assemble a broadly representative group consisting of consumer representatives and staff members of NIHR, the National Council on the

Handicapped, the Rehabilitation Services Agency, a state vocational rehabilitation agency, a Rehabilitation Research and Training Center, and the Social Security Administration. We solicited the group's views as to the feasibility of a center for research on disability and its possible role and functions. We then submitted to them some assumed objectives of the proposed center and twelve possible research topics which they were asked to rate. Each member was then asked to suggest additional issues or topics. (Some of these results are included in Appendix A.)

We intend to identify the policy issues relevant to the priority areas addressed in this proposal by using somewhat the same techniques we used to identify issues in our feasibility grant. We would choose the members of the consultant groups on the basis of their interest and expertise in a particular area. The process is illustrated below.

1) The Economics of Disability

The Bureau has pioneered in the area of the economics of disability. Individual staff members are acquainted with persons working in this field and a number of the persons will be consulted in much the same way we have consulted the committee in the feasibility project. We would select candidate issues and have our consultants rank them as to relevance and policy importance. We would also, as in the feasibility project, encourage these individuals to suggest additional issues not on the list. As with all our consultant groups, we would give a prominent place to consumer representatives.

The economics of disability encompasses a multitude of issues. At the individual or micro level, one can think of the onset of disability imposing psychic and material losses on the individual. In this regard, the economics of disability is concerned with the actions of individuals as they strive to

regain their former levels of satisfaction or well-being. At the macro level, the economics of disability is concerned with the allocation of funds among public and private programs. It seeks to measure the equity, adequacy and efficiency of these programs. For example's sake, one could identify the following issues in the area of the economics of disability:

1. What effect would the expenditure of additional funds on rehabilitation have on the overall costs of disabiity?

2. How can the costs and the benefits of various service programs be measured?

3. What extra work expenses and other costs are incurred by handicapped persons over and above what they would have to face were they not handicapped?

4. What are the economic consequences of a particular impairment or injury, such as spinal cord injury? How can these consequences be measured?

5. How can the economic value of disabled persons who are rehabilitated to homemaker status be measured?

2) Work Disincentives

The work disincentives area is a part of the economics of disability. With the onset of impairments, individuals may face a choice between work and benefit status. The higher the benefit levels and the easier the entrance requirements, the more likely impaired individuals will have an incentive to choose benefit status and a disincentive to work. The choice for impaired persons without labor market experience may be between benefits and independent living status. In the work disincentives area, the following issues could be suggested:

1. How can the effects of a change in benefit levels on the supply of

labor best be measured?

2. What are the extra medical expenses of different types of handicapped persons and what is the effect of a loss of governmentally-provided medical care insurance on labor force participation?

3. What is the relationship between disincentives and transportation? How can the benefits and costs of additional types of transportation for disabled persons be measured?

3) Habilitation of Children

Elizabeth Boggs and the UAF have had a great deal of experience in the area of habilitation of children. We understand habilitation to include the interventions and services necessary to assist disabled children to acquire skills and to progress developmentally. The term is equally applicable to developmentally disabled adults. Whereas rehabilitation addresses the problems of how to recoup or compensate for skills lost due to trauma or illness, habilitation refers to the acquisition of skills not attained because of the early onset of the disability. We suggest, as examples, the following issues which would be submitted to an appropriate group of specialists and consumers for consideration:

1. What has been the impact of neonatal intensive care units on the incidence of disability among surviving infants?

2. Given that neonatal intensive care units have a positive impact on survival rates, what changes are required in our social and economic policies as a result?

3. How can the need for new educational and intervention programs be assessed? How can their impact be measured?

4. What are the characteristics of preschool services made available to

children ages 0-3 and 3-5, and what is the relationship of these services to development?

5. What is the demand for respite services for family members where a disabled child is present? How can these services be financed?

6. What is the role of siblings in the family when disabled children are maintained at home?

7. What is the impact of a disabled child on the family's economic position?

4) The Training and Deployment of Professionals in Rehabilitation-Related Disciplines

Investigation of this subject will be shared by the Bureau and the UAF since it falls neatly into areas of interest and expertise common to both groups. There is an economic component to the supply and demand for professionals in any field. The allocation of persons across disciplines is governed by the differential rewards accruing to persons in the several fields subject to all types of lags and constraints. Examination of the literature and the research on the supply of labor to particular professions and the returns to investment in human capital will be relevant here.

The UAF will be interested in those aspects of the problem that pertain to emerging needs in the fields of their concern. Under PL 94-142, children may receive "related services" (occupational, physical and speech therapy) if prescribed in their Individual Educational Plan (IEP). This gives rise to a number of issues: What is the current supply and demand for such therapists to work with severely handicapped children? Are the training facilities adequate to meet the anticipated demand? Are the anticipated salary levels and earnings opportunities sufficient to attract the forecasted number of persons?

The deployment of professionals also encompasses other issues of import. What has been the impact of the efforts of the American Academy of Pediatrics and the Office of Special Education and Rehabilitation Services to link sophisticated pediatric evaluation to special education planning processes? How can regular education teachers be retrained to facilitate the mainstreaming of children with handicaps? Research on retraining might include future methods of teacher education and compensation issues, as well as an examination of successful programs in operation.

The supply of professionals might be increased by the retraining of special education as well as regular education teachers. At least two possibilities might be explored. Special education teachers who are currently employed in the infancy and preschool fields might be retrained to meet the programmatic requirements of infants who have been served by the Neonatal Intensive Care Units. Retraining might also be the solution to the growing demand for special education teachers with the expertise in employment and vocational options that would enable them to help students make the transition from school to work.

The field of adult rehabilitation is also undergoing changes that will have consequences for the rehabilitation professions. Research as to the market for professionals in the following areas could be examined:

1. Personnel to work in community living arrangements for the developmentally disabled, especially for those with severe behavior problems and extensive physical handicaps.
2. Persons to provide services related to independent living.
3. Case managers.
4. Placement counselors trained to provide meaningful work opportunities for persons with developmental disabilities.

5. Persons to work in community services. Also of interest would be the possible ways to transfer professionals now working in institutions to positions in community services.

In similar fashion, we would also seek to identify the issues in the area of community-based care. As illustrated below, some of the issues will be cross-cutting issues covering more than one area.

The choice of issues is crucial since it defines the research which will be examined. Undoubtedly, some important issues will be raised by the queries we receive from administrators faced with important questions. We would welcome such inquiries, but we do not believe that the center's work should be reactive. The center must be able to anticipate issues. It is obviously preferable to prepare for the crisis of tomorrow rather than to solve the problems of yesterday.

B. Identifying the Research

Once the issue has been formulated, the next step would be to identify the research in that area. Here we would proceed on at least two fronts. One would involve the use of NARIC's services to search the relevant data bases. The other would involve a search on the part of the center's staff based on the suggestions and leads obtained from consultation with experts and persons in the field. We will supplement NARIC's search of the data bases with the reports of NIHR-funded research. We expect to establish an ongoing relationship with NIHR so that we can be apprised of reports as they are received by NIHR. We will also establish relationships with Research and Training Centers so that we can anticipate the work they will be completing in the near future. In addition, we will make use of the traditional procedures by which researchers in an area assure themselves that they have examined the relevant literature. In a

well-researched area, the process involves getting to the person or persons who have worked in the field, talking to them or examining their latest output, checking the bibliographies they have provided or the readings they have suggested, and then following through from there. As anyone who has been through the process knows, it is a type of detective work that scholars find fascinating. It is not a mechanical process that can be entrusted to clerical persons except at its most basic level, and the more expert the researcher is in the field in which he or she is delving, the shorter and the more efficient the process.

C. Evaluation of Research

The next step is the evaluation of the research product identified. Once the relevant research in the area of the identified issue has been collected, we propose that it be put through a series of screens. There are several ways in which this might be done, and we would devote a good portion of our time in the beginning of this project to the development and testing of these screening criteria.

We have had some experience in evaluation of research in another project funded by the National Science Foundation (NSF). The results of that project were reported in a monograph, An Evaluation of Policy-Related Rehabilitation Research.[7] We learned several valuable lessons from that experience which should stand us in good stead in the operation of this center.

1. Not all reports labeled as research reports truly fall into that category. Some are reports of demonstrations without any discernible research component, some are descriptions of service programs, and some

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[7] Monroe Berkowitz, Valerie Englander, Jeffrey Rubin, John D. Worrall, editors, (New York, Praeger: 1975).

turn out to be progress reports with results promised some time in the future.

2. It is not possible to evaluate research based upon summaries of the work. The summaries we examined proved to be cursory accounts that failed to answer the basic questions asked. We found that full-text copies including all the appendixes were necessary.

3. We also found that examination of titles of research reports proved to be misleading at times. Use of key words and descriptors helped and their use has proliferated since the date of our inquiries, but it is likely that only perusal of the full text will enable us to judge quality and relevance.

We plan to select and screen research for both relevance and quality. By relevance we mean the relationship of the research to the issue being examined. Sometimes these relevance decisions are routine, but at times, they are a bit more complex, especially when the research report may contain some small finding that is not central to the report but which may shed important light on the issue being examined.

Obviously quality checks are more difficult to administer. In the NSF report, we used a fifteen page checklist which was administered by the specialist teams examining the research. In summary, the checklist asked for information on the following:

1. General Information. This information was used for classification purposes. In addition to title and name of granting organization (if any), we listed the hypothesis, discipline, subject matter, dates of beginning and end of the project or inquiry, and similiar information.

2. Sampling Information. Description of the sample and how it was

selected. Generalizability of the sample including such factors as sample size and representativeness, procedures for drawing sample, etc.

3. Data Gathering. Data sources (questionnaires, tests, interviews, or other sources), treatment of nonresponses, refusals and dropouts and effects on the results.

4. Methodology and Data Analysis. Type of design (experimental-nonexperimental), follow-up, operationalization of treatment and outcome variables, clarity and testability of hypotheses, and statistical procedures, i.e., descriptive statistics, associational analysis or multivariate analysis.

5. Results. Conclusions of the project, and pertinent information on uncontrolled external influences or internal program characteristics.

6. Policy Utility. General usability of the project or procedure; doubts or difficulties in putting results to use; usefulness of empirical findings; conceptual contributions and methods; accessibility and manipulability of independent variables; ethical, economic, and organizational feasibility of using the variables in practice; and conflicts with other results.

7. Ratings. Two kinds of ratings were sought on each project or report evaluated. One was a methodology-data analysis rating and the other was a policy-utility rating.

Obviously, the type of quality rating to be done with research evaluated by the center would differ from that used in the NSF project where the purposes were different and the scope narrower. But the quality checks used in the NSF project are illustrative. The absolute necessity for a rigorous quality screening or evaluation stems from the desire to use research for policy

purposes. If the results are not generalizable, or if they rest on shaky foundations, it would be foolhardy to promulgate them for policy purposes. We believe the center must be prepared to make careful quality judgments based on tested criteria.

Any process of evaluation is difficult and runs the risk of excluding some work which should be included. But to include all work which labels itself as research without any screening is to overload the communication channels so that the target audiences either cannot absorb the huge volume of information or learn to distrust it after several bad experiences. We think that the preferable alterative is to screen on the basis of widely disseminated criteria so that the ultimate user of the information knows the basis on which the product he or she is using has been selected.

D. Summarizing the Research

Our intention is to produce several types of summaries. One type would be the synopsis of a single research report, book or article. Such single-subject summaries would be reserved for important reports, especially those with promise of timely application.

A second type would be the analytical summary of a body of research impinging on a particular issue. An analytical effort of this kind would also identify gaps in the body of research and point to new lines of inquiry.

One important output we foresee is a a DISABILITY PRIMER. Eventually, this would appear as a book with individual chapters devoted to single disability issues. The exact subjects would be chosen only after a great deal of consultation with people in the field. For sake of example, assume that it is decided to devote a chapter to a subject such as "job coaches." The chapter would explain the terminology the reader should know and the issues most central

to the subject at hand. It would also summarize the research that has been done and comment on what that research does and does not tell us about the issues in the area. (The research products themselves would have come from the earlier stages of the work.) The chapter would conclude with suggestions for further research in the area.

The primer could fill a gap in the types of information available to persons who seek reliable analyses of issues in the field. Possibly, the main difficulty in putting together such a primer would be the selection of the subject matter areas or the issues to be explored. Obviously there are too many such areas and issues for all to be included and the choice of what to include and what to leave out will not be an easy one.

To meet the need for some more succinct forms of output, we propose that we begin to compile ENCYCLOPEDIA entries. We would expect to reproduce these entries in single sheet form for distribution. We think they could become an ideal method for summarizing the state of knowledge on a particular subject. Eventually they could be brought together into a volume, although we would expect that the process would take longer than the three years allocated for this project.

Perhaps an example would make the distinctions among these several types of outputs clearer. One could begin with a subject, say, medical care for disabled persons. The primer chapter would treat the issue broadly. It would summarize what is known about the issue and would identify the questions which are asked about it. It might examine the following problems:

1. How can one identify the costs of medical care which arise solely because of a person's disabling condition?

2. What problems have arisen in the provision of medical care insurance

for disabled persons?

3. What research has been done as to the feasibility of including rehabilitation services in health insurance policies?

4. What research has been done and what does it tells us about the incentives and disincentives that loss of insurance coverage may create for beneficiaries who leave the rolls to return to work?

The challenge in writing the primer chapter would be to identify the broad range of issues, to select out several issues for more intensive examination, to summarize what we know about the subject, and to identify the gaps in our knowledge.

No matter how good a job is done with a primer chapter, there would still be considerable room for encyclopedia entries. What do we know about the health care experience of persons with particular types of disabling conditions? What has been the experience of private insurers with the provision of rehabilitation? How does the accident record of disabled persons compare with that of others at the workplace?

Obviously if we were to learn more about the broad area of medical care for the disabled and to disseminate our findings through the kinds of literature we have described, we would be able to provide valuable input into some basic policy decisions. There is not one but a multitude of policy issues here:

1. Does the anticipated loss of Medicaid and Medicare coverage by impaired individuals who are considering a return to work constitute a disincentive which is significant enough to justify some action on the part of Congress?

2. Should alterations be made in how Social Security accounts for the extra work expenses involved when an impaired person returns to work?

3 Are present arrangements for the inclusion of rehabilitation in private

and group policies sufficient to provide incentives to develop an optimal strategy for the prevention of disability?

Note that a broad issue such as medical care for disabled persons is a cross-cutting issue which comes under several of the priority areas including the economics of disability, work disincentives and of course, the habilitation of children and community care facilities. The fact that a single topic can cut across so many of the priority areas and the fact that the issues can be stated in so many different ways serve to emphasize the importance of the first stage of the inquiry, the identification of the issues.

E. Experience of other Countries

We are not so chauvinistic as to believe that all relevant research on these issues is taking place in the United States. We have become familiar with some of the relevant foreign research through the Bureau's work in the Rehabilitation International (RI) project and through the work we have done as part of a World Rehabilitation Fund (WRF) fellowship.[8] Getting research input from foreign countries has all of the difficulties one would encounter in the United States plus the added problems of language and cultural barriers. We propose to begin the process by having RI coordinate the work of five researchers who will investigate the research done in their countries in the area of disincentives and labor supply. We expect to work together to devise a format for publication of the research in the International Journal of

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[8] Research in this area is reported in the International Journal of Rehabilitation Research (Heidelberg: HVA Publishing Co.). Some of the activities in other countries are summarized in two recent reports written by Monroe Berkowitz: "Disability Systems--A Cross National Comparison," a report prepared for presentation at the RI conference on Social Security Disability programs, Baltimore, MD, April 15, 1986, and "Social Insurance and Rehabilitation--The Netherlands, Sweden, Finland and Israel," Fellowship Report for the World Rehabilitation Fund, September-October, 1985.

Rehabilitation Research and for presentation of our findings at the RI World Congress to be held in Tokyo in 1988.

If this type of collaborative endeavor is successful, it will be expanded to other areas. Preliminary discussions are now taking place in the area of habilitation of children. RI, which is currently involved in a UNICEF project (Technical Support Program), and the Rutgers University Affiliated Facility are both eager to explore the possibilities of bringing to bear foreign experience in studying the transition from school to work. It is expected that the project will be able to utilize the research sponsored by the Organization for Economic Cooperation and Development (OECD) in this area.

F. Development of a Directory

The development of a directory of agencies and organizations active in the area of disability policy research would be most helpful both to researchers and to administrators and others concerned with the formulation of public policy. We anticipate that the directory will emerge from the work carried out in the first year of the project, as we identify sources of information and acquire some sense of the interest of the various groups.

During the first year of the project, we envision the development of a standard format for directory entries using one of the standard software packages modified for our use. It is essential that any directory be accurate and kept up to date. As we see it, it will take the first year to develop a format and to test its use. During the second year, we expect to have the directory functional and accessible by computer with hard copy on request. It would not be until the end of the second year that we would produce a hard copy printed directory, and then only if we were assured that the entries exhibited the type of stability that would not render such an undertaking outmoded before

it could be used.

To have the maximum usefulness, the directory should contain not only names, addresses, phone numbers and other identifying information but also a succinct description of the work done by the agency or organization, together with a classification of the types of work and some notion of its availability. We expect to work closely with NARIC in the development of some of the necessary concepts.

G. Summarizing the Project Design

We can summarize the project design by tracing the flow of research products through the center. A version of the process is shown in Chart 1.

I. Research results in the form of reports, articles, chapters in books and entire volumes come into the center from various sources including:

A. NARIC, in response to a request for a specific search.

B. Recommendations made by experts or expert panel.

C. Literature searches conducted by center staff.

D. Regular input from NIHR, Rehabilitation Research and Training Centers (R and T centers) research institutes, and universities.

E. Other. (As the research utilization center's functions become more widely known, we would expect researchers to send in reports on a voluntary basis.)

II. Research products are classified into two categories.

A. Relevant to ongoing inquiries and subject to initial quality checks.

B. Not relevant to current inquiries. These products may be:

1. Made the subject of a single issue summary.

2. Held in reserve after initial rough classification.

III. Research products relevant to current inquiry are subject to further analysis and evaluation by center staff, by expert panels or by both. Research products that survive the process may then be used in various ways:

A. Single subject summary for immediate distribution.

B. Basis for an encyclopedia-style article.

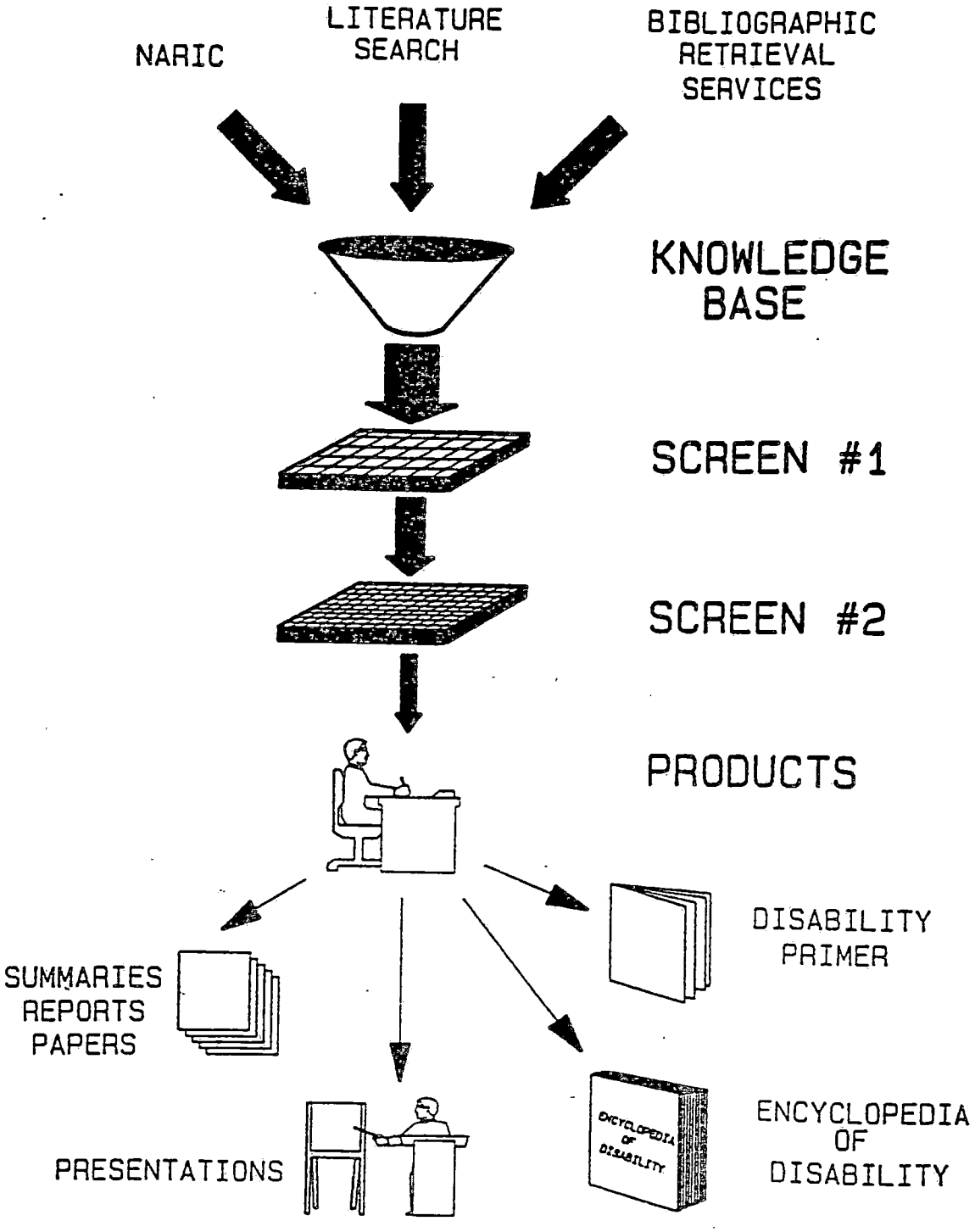
C. Input into a chapter in the disability primer.

IV. Based on inquiries into a particular area, gaps are identified and suggestions made for further research and investigation.

In a sense, the process has come full circle. Our exploration of an area will issue in reports of research that are widely disseminated. It will also lead to the identification of the gaps in our knowledge and to suggestions for new lines of inquiry--results which in turn might trigger a request to NARIC and other input sources for a new search. In this way, the process would begin all over again.

CHART 1

ISSUE ANALYSIS PROCESS



4. Key Personnel

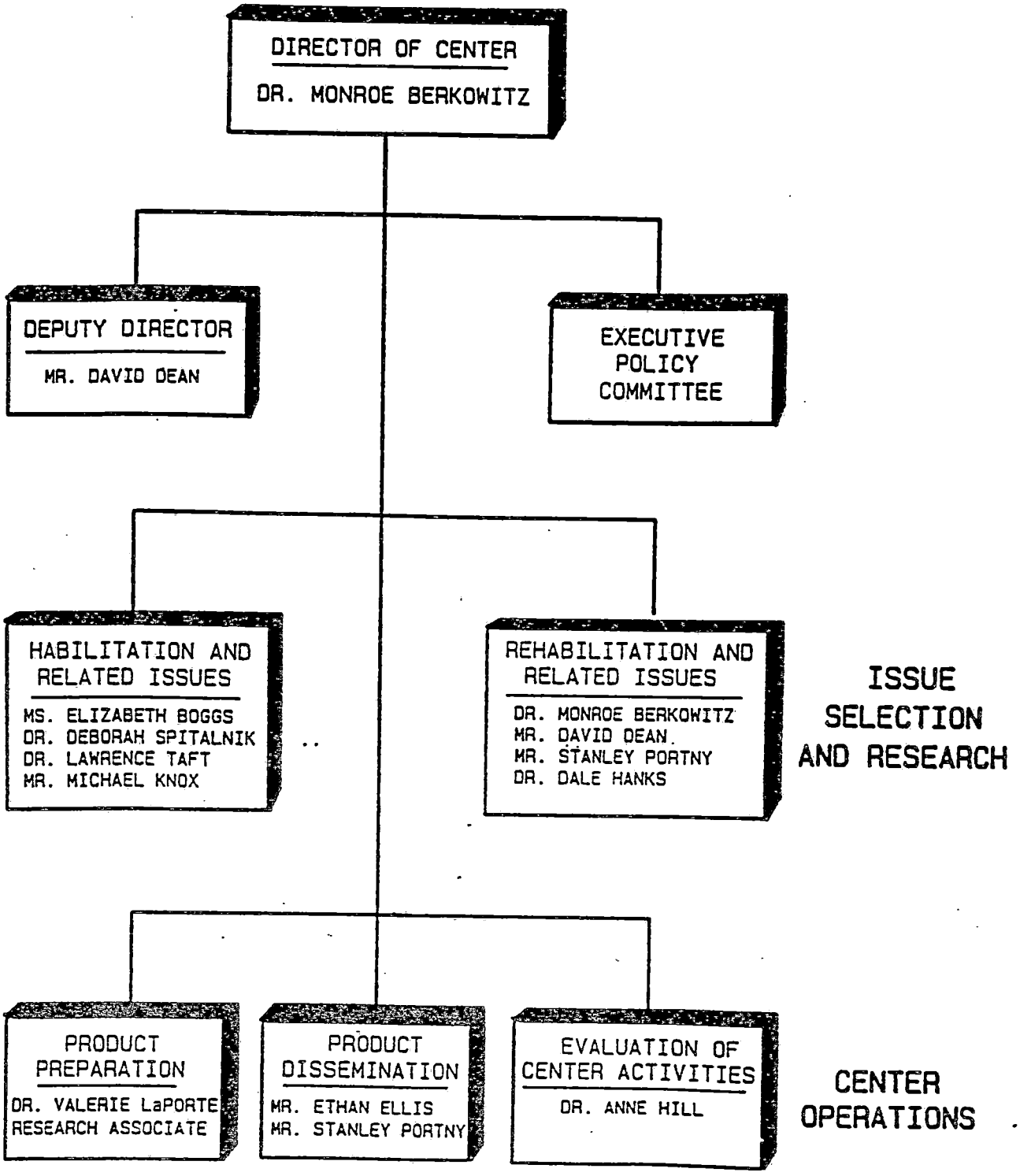
The project will be a principal activity of the Disability and Health Economics Section of the Bureau of Economic Research. For more than a quarter of a century this unit has been engaged in disability policy research, much of it focusing on social insurance programs and rehabilitation. Its emphasis has been on socioeconomic aspects of disability issues. It will be joined in this project by NARIC, Dr. Elizabeth Boggs, the University Affiliated Facility of the Rutgers Medical School, Ethan Ellis, Rehabilitation International and selected foreign researchers, Dale Hanks, Stanley Portny, and panels of consultants. In conformity with Bureau practice and policy, the persons who will be responsible for making basic decisions include those who are themselves handicapped or who are the parents of handicapped children. Chart 2 illustrates the proposed organizational structure of the research utilization center.

The principal investigator will be Monroe Berkowitz, Professor of Economics at Rutgers University, who will devote 25 percent of his time to the center. His primary research interest is in economic aspects of disability, with particular emphasis on measuring the impact of rehabilitation measures on the overall costs of disability in the United States and other countries. He has been the principal investigator of Bureau projects which have been financed by such agencies and organizations as the Social Security Administration, the U.S.Department of Education, the U.S. Department of Labor, the National Science Foundation, state vocational rehabilitation agencies, state workers' compensation agencies, the Paralyzed Veterans of America and NIHR.

Several Rutgers persons will be working on this project. They include David Dean, Research Associate, who is skilled in the area of the computerization of

CHART 2

PROPOSED ORGANIZATION CHART



information and the application of econometric techniques to rehabilitation issues. He will spend approximately 25 percent of his time on the project. Professor M. Anne Hill of the Department of Economics will also participate, devoting 12 percent of her time to the project. Professor Hill has recently completed a study of the client populations served by the blind rehabilitation agency in the state of New Jersey and is now working on a survey of the demographics of disabled persons in the state of New Jersey. With Monroe Berkowitz, she is coeditor of Disability and the Labor Market: Economic Problems, Policies and Programs.

Working full time on the project will be Dr. Valerie LaPorte, who will serve as the project manager for the intake of materials and for the production of publications. Dr. LaPorte has worked with the Bureau on several projects. She is coeditor of two volumes based on Bureau projects: Alternatives in Rehabilitating the Handicapped[9] and Reform and Regulation in Long-Term Care.[10] She is currently revising and editing a forthcoming Bureau study on the costs and benefits of rehabilitation.

Ethan Ellis, Staff Coordinator of the New Jersey Governor's Task Force on Services to Disabled Persons, has worked with the Bureau on our planning grant for the establishment of a disability policy center. We expect him to use his experience with rehabilitation agencies and advocacy groups in our outreach activities.

In a current project, "Enhancing the Understanding of the Economics of Disability," we have been working with the Virginia Department of Rehabilitative Services and Stanley E. Portny Associates, Inc. (SEPA). With Dale Hanks,

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[9] (N.Y.: Human Sciences Press, 1982)

[10] (N.Y.: Praeger, 1979)

Director of Planning Policy, Development and Research for the Virginia DRS and Stanley Portny, President of SEPA, we have developed a method of examining rehabilitation experiences in three states. Dale Hanks and Stanley Portny have also cooperated in the execution of the planning grant for the feasibility project. Mr. Hanks would serve as our liaison with state rehabilitation agencies and Mr. Portny would help develop our procedures and assist in the dissemination of information.

We intend to rely heavily on the experience and the expertise of Elizabeth Boggs in the area of community based care and the habilitation of children. She will devote approximately 12 percent of her time to the project, a portion of which will be donated. Dr. Boggs will help in the identification of issues and of key consultants in these fields. We would rely on her broad knowledge to identify research products and persons actively engaged in research. Dr. Boggs has been a pioneer in the field of developmental disabilities and most active in promoting the first legislative measures in the area. She is currently serving on the New Jersey Governor's Task Force on Services for Disabled Persons as well as a host of other committees.

Working closely with Dr. Boggs in these areas will be Dr. Lawrence T. Taft, Professor and Chair of Pediatrics at Rutgers Medical School (UMDNJ), who will be donating his time to the center. Dr. Taft is an expert on the habilitation of handicapped children and the training of medical and allied health personnel to work with disabled children and their families. Internationally recognized for his work in cerebral palsy, Dr. Taft has written and lectured extensively on childhood disability. He is the principal investigator of the Rutgers Medical School UAF.

Also working with the center will be Dr. Deborah M. Spitalnik, Executive

Director, and Michael Knox, Administrator of the UAF, each of whom will be devoting approximately 10 percent of their time to the center, a portion of which will be donated. In addition to her experience as a clinical psychologist, Dr. Spitalnik has extensive experience in public policy, staff training and delivery of services to persons with developmental disabilities. Michael Knox has substantial experience in planning and policy analysis in human services, including Title XX of the Social Security Act and other generic social service programs.

The mission of the UAF is to enable persons with developmental disabilities to live in the most dignified and independent manner possible. The UAF attempts to implement this mission by improving services to developmentally disabled persons through the interdisciplinary training of personnel, the conduct of research, and the dissemination of research and information on developmental disabilities. One of the UAF's current initiatives involves a three-year grant from the New Jersey Developmental Disabilities Council. This project addresses the problems of case management services to children, primarily provided through the state's Special Child Health Services Program, as well as services to adults through the Division of Developmental Disabilities.

The Rutgers UAF is part of a professional network of approximately fifty programs nationwide. Each program is mandated to provide research and disseminate information about developmental disabilities. Such a network provides an already established mechanism for identifying policy research and disseminating research summaries.

We welcome the cooperation of NARIC in this project. NARIC is a rehabilitation research library located at the Catholic University of America and funded by NIHR. Established in 1977, the library has undertaken to:

1. Facilitate dissemination of rehabilitation information;
2. Promote utilization of rehabilitation research;
3. Serve as an archive for NIHR and Rehabilitation Services Administration (RSA) documents; and
4. Make information on assistive devices available to disabled consumers, researchers and professionals serving disabled persons.

Ms. Susan Flowers, Director of NARIC, will be cooperating with us in the identification of policy issues and current gaps in the information. W. Edward Rorie will serve as the primary database researcher and Fredlyn Karp will be available for advice on dissemination strategies and publications development. We will compensate NARIC for costs of materials and for some direct search time.

In carrying out our project, we will not duplicate services already available from NARIC. These include the search of NARIC's own rehabilitation materials as well as the numerous other data bases available through Bibliographic Retrieval Services (BRS) Information Technologies. Among the data bases which will prove useful will be the Index to U. S. Government Periodicals (GOVT); HEALTHLAWYER, A bibliographic data base devoted to health law; and the CATALYST RESOURCE ON THE WORKFORCE AND WOMEN DATABASE (CRFW), a collection of materials on career and family issues and working women.[11] Disability issues are part and parcel of other broader issues, and it will be necessary to disentangle the disability-related aspects from the general topics. In seeking out material on disability issues in the data bases, we will rely on the guidance of NARIC personnel and the librarians at Rutgers University.

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[11] These and other data bases are described in various issues of the BULLETIN (Latham, NY: BRS Information Technologies).

We have worked with Rehabilitation International on several projects and we look forward to their participation in the center's activities. RI will coordinate the foreign experts who have agreed to work with us on the labor supply question. These persons are Han Emanuel of the Social Security Institute in the Netherlands; Edward Palmer, Director of Research, Social Insurance Board, Sweden; Helen Bolderson, Department of Government, Brunel University, England; Ian Campbell of Massey University in New Zealand; and Risto Seppalainien, Managing Director of the Insurance Rehabilitation Agency in Finland. This group might expand in the future.

The Bureau of Economic Research at Rutgers marshals the expertise of fifty-five faculty in economics who represent a variety of specializations. Several areas are formally organized as research sections and one of these is the Disability and Health Economics section.

Rutgers University is the only university in the country with a colonial background that is also a land-grant college and a state university. The twentieth largest university in the nation, it has an enrollment of over 49,000 students. Rutgers is an equal opportunity employer that receives over $25 million in grants and contracts to conduct essential research projects. It is in compliance with all equal opportunity rules and regulations of the Department of Education.

5. Evaluation Plan

If the policy research utilization center is to make a lasting impact on the formulation of disability policy, it will take some time to set up and test the procedures for the identification of issues and the screening of research. It is expected that a good part of the first year will be occupied with the development and the testing of these procedures. As the system matures, we expect to see a flow of research product through the screening and summarization processes; the output generated will be in the several forms already discussed above. Initial evaluation will be in terms of adherence to the timetables set up for the development of the different procedures.

When the operations of the center swing into full gear, the meaningful evaluation will be in the measurement of the uses to which the product is put. We intend to devise an evaluation instrument which will focus primarily on utilization of products of the center. We take as one of our models the Social Sciences Citation Indexes where one can look up the research output of a person and examine how and where it is cited by others in the field. In somewhat the same way, we propose to query users in the second year of the project to determine the uses which they have made of the center's output. Based on what we find, we will then interview a selected number of users to determine something of the strengths and weaknesses and timeliness of the product. No matter how elegant the output of the center might be, if it is not utilized in the day to day formulation of policy in a direct or an indirect way, the project will not be doing its job.

6. Plan of Operation

The overall direction of the center will be the responsibility of the principal investigator. Assisting him will be David Dean. The management of the day to day operations will fall to Dr. Valerie LaPorte, assisted by one person from the Bureau's junior staff and clerical personnel. The evaluation functions will be under the general supervision of Dr. Anne Hill.

In general, the policies governing the spending of funds, the compensation of personnel, and general personnel matters are those mandated by Rutgers University. The Research Contracts Division of the University performs a general oversight and auditing function.

Responsibility for liaison with outside consultants will lie with David Dean. We will work closely with Ethan Ellis in the planning of any conferences and meetings. Mr. Ellis's office is at the Institute of Management and Labor Relations at Rutgers. The close proximity of the UAF should also facilitate our working with them.

In terms of timing, the first three months of the project will be spent in defining functions, duties, and procedures; and in locating consultants who might prove useful in the several functions of identification, classification, forms of output, etc. During the second three months, we intend to go through the process of formulating screening criteria and testing these on research output in each of the priority areas. Months six to nine will be spent in testing the system which has been set up. At the end of nine months, we will evaluate the system in terms of our objectives, and make the necessary revisions in procedures and the assignment of personnel. Months nine to twelve will be spent in operating the system, although we will continue to test it in light of

our plans. We want to be certain that the sources of referrals are working, that research products are being sent for evaluation as promised, that screening criteria are being interpreted in a uniform fashion, and that summaries that are produced meet the tests of readability, applicability and fairness to both the researcher and the user.

Our management plan clearly entails a number of intermediate evaluation schemes. The eventual evaluation, however, will not be in terms of these process goals, but in terms of the extent of utilization of the final product in the formulation of policy.

Chart 3 portrays our schedule for the first year of operation.

PROPOSED SCHEDULE FOR FIRST YEAR OF CENTER OPERATION

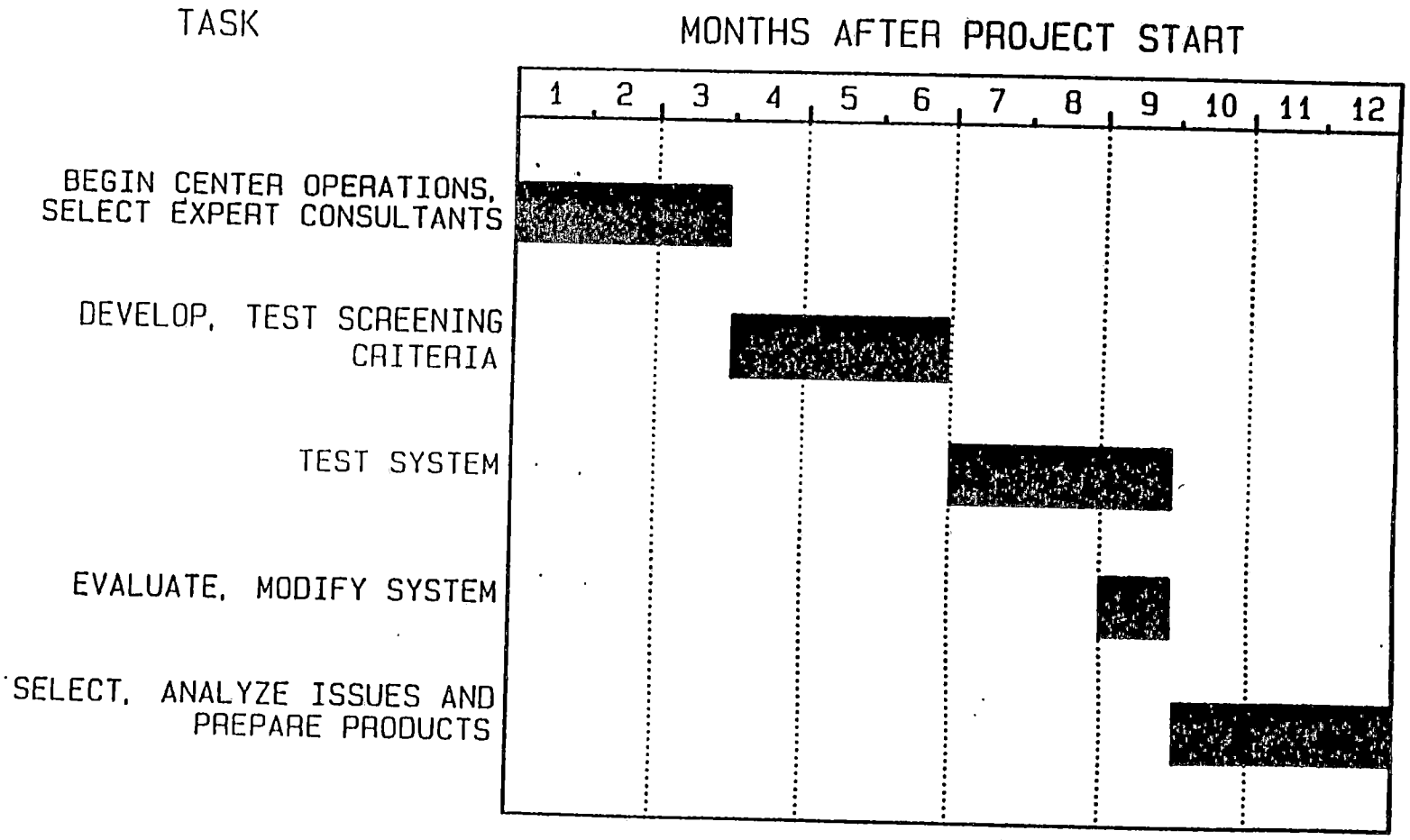

CHART 3

7. Adequacy of Resources

We are fortunate in that we can take advantage of the facilities of Rutgers University. The University library contains over 2,000,000 bound volumes and over 1,000,000 government documents, pamphlets, maps, and other materials. In addition, the Bureau maintains a library with an excellent collection of rehabilitation reports and data on disability-related organizations and disability programs. The Bureau employs the computer facilities maintained by the University and a consortium of the University and other educational institutions in the state. In addition, we have available the department's micro-computer center and personal computers and terminals within the Disability and Health Economics research section. The section has access to large scale data sets such as the various Social Security Surveys of Disabled and Non-Disabled Adults. Access to such information has proven to be useful as we evaluate research findings of individual projects.

Computer and systems consultants within the Bureau will devise the initial flow of research products through the various processes and will be responsible for the system checks. We will also utilize the Bureau's production and mailing systems for the dissemination tasks. If these become overburdened, we will use the services of a sheltered workshop in New Brunswick which specializes in these tasks.

The University has demonstrated its commitment to the proposed center by its approval of this application, which is submitted formally on behalf of the University. The University has generously supported the work of the disability section for the last quarter century and has become increasingly interested in this area. The Bureau has a tradition of cooperation with other units of the

University, including the School of Education and the Graduate School of Social Work. A new Institute for Health, Health Care Policy and Aging Research under the direction of Dr. David Mechanic has recently been established. The principal investigator and Dr. Hill are members of that Institute and we expect to work with other Institute members on components of this project.

8. Budget and Cost Effectiveness

We are cognizant of the budgetary restraints and how these must limit the center's operations. As we mentioned above, we are fortunate to be based at a University and to be able to take advantage of faculty members with a wide range of expertise. In our NSF project, we used faculty personnel from the Graduate School of Education, the Graduate School of Social Work, and the Departments of Psychology, Sociology, and Political Science, as well as the Department of Economics. We have cooperated with faculty members in these units in the past and confidently look forward to their cooperation as the center gets underway.

We do not expect to be able to call on faculty members and outside consultants indefinitely without providing some compensation. As part of our planning grant for the feasibility of establishing a disability policy center, we have begun to explore the possibility of outside funding from several private sources. If the policy research utilization center were funded by NIHR, we would expect to supplement funding from other sources so that the budget might be brought up to a more realistic level. In the meantime, we shall get started with the budget provided and seek to garner as much help as possible from resources at Rutgers.

We think it will be extremely cost effective to cooperate with NARIC, the UAF and RI. In each of these cases, we will take advantage of work these units are already doing. This has the great advantage of eliminating needless duplication of resources, time and effort--a measure which seems to be in line with current governmental efforts. We would, of course, expect to pay for direct expenses incurred by NARIC in duplicating hard copy or providing other services of this kind. We also recognize our responsibility to cover extra or

marginal costs incurred by other organizations. These sums, however, are considerably less than the cost of producing these reports or analyses from scratch.

Our operating plan calls for us to reach out to consumers and expert consultants in the identification of issues and research, the development of screening criteria and numerous other tasks. We expect to seek the assistance of Rutgers faculty in these matters, but we also recognize the need to call on outside personnel. For this purpose we have provided funds for consultants. We believe that this will be the most cost effective way to use the center's funds, at least in the first year. We have kept the full-time staff personnel down to a bare mininimum. Should more funds become available in future years as the center's products gain credibility, we would look forward to employing additional personnel on a full-time basis.

THE NATIONAL DISABILITY POLICY CENTER

Sponsors of The Disability 2000 Survey

23 June 1986

Nancy A. Sims
Assistant to the President
W.K. Kellogg Foundation
400 North Avenue
Battle Creek, Michigan 49017-3398

Dear Ms. Sims:

I am writing to request a "founding grant" or start-up funds to launch "The National Disability Policy Center."

The National Disability Policy Center will be the nation's first think tank devoted exclusively to disability policy research and education. It is inspired by several convictions developed during the past two years as a Switzer Distinguished Fellow of the National Institute of Handicapped Research, to wit: a vacuum in disability policy research and the accruing negative consequences for society and disabled persons and their families, some serious wrongheadedness in much of the research that is done, a lack of responsiveness by venerable disability programs to changing conditions, findings that suggest disability is potentially the most pressing health care and social welfare issue of the late 20th and early 21st centuries, and widespread interest in new solutions to disability problems by the federal government (Congress and Executive agencies) and business -- an interest born of an emerging awareness of disability's increasing demands and a sense of helplessness that little original thinking, useful debate, or innovative strategies are available.

These several circumstances create a unique and timely opportunity to influence the policies and actions of both the public and private sectors to "invent a future" for disabled Americans and avert a predicted disability "crisis" through original research and concrete, feasible policy and program recommendations. Although disability-related policy problems are studied in various settings -- including universities, eclectic think tanks, and government agencies -- no other research group is committed to: advancing the nascent field of "disability policy studies," be as thoroughgoing in the range of issues research, or fashioning new ways to think about ("create a vision of") key public purposes from a disability perspective. In addition to these activities, the Center will be an "independent voice" commenting on public disability actions and "current events" of disability interest.

The points raised in the two preceding paragraphs may be readily illustrated. The vacuum in disability policy research and scholarship can be appreciated by walking into any bookstore. One can collect armfuls of books on health policy, social welfare according to every ideological enthusiasm, the "aging" of the American population and its social implications, the causes and remedies of unemployment, histories of even arcane subjects, and broad discussions of the "future" of America, and find little mention of disability among any of these topics, and few (if any) comparable works on disability. Yet, disability bears

an important relation to each, and a disability perspective offers each fresh insights. For example, with regard to health, one key way the government measures the success of the "health care system" is by death rates (infant mortality being a highly visible example). Death rates have fallen dramatically over the past century, are now the lowest ever, and are projected to decline even further (albeit more slowly). And they also serve to provoke debate -- how can we do better?

But by a disability standard, conclusions that the "nation's health" is improving are not so easily made -- e.g., between 1966 and 1979, the number of people reporting "severe disabilities" on federal health surveys almost doubled. Would not a "disability rate" be a more sensitive measure of national health, more revealing of the quality of health, more appropriate to a time when medical science is making startling progress in keeping people alive longer (perhaps to the limits of the conventional human life span), and as a spur to action? Yet, remarkably, disability prevalence studies are rarely done, routine disability statistics never reported, and only a dim consciousness of this critical purpose of health care presently exists.

And virtually none of the commentators on the important and emotional issue of poverty -- from Michael Harrington (The Other America) to Charles Murray (Losing Ground) to John Schwarz (America's Hidden Success) -- discuss the highly suggestive evidence that between 30% and 75% of poverty in America (depending on other factors such as race and education) can be traced to a disabling health condition (via a 60% jobless rate among working age disabled people). Or that despite impressive inroads in combating poverty over the past 25 years, poverty among disabled people today is at the same level as among the general population in 1959, and 3 times the present national average.

Lack of vision about many public purposes and proper analyses of national issues are not the only casualties of the paucity of disability policy research. The widely-reported debacle over the summary dropping of hundreds of thousands of persons from the Social Security Disability Income (SSDI) program rolls from 1981 to 1984 was the result of highly suspect government data on the number of allegedly "ineligible" beneficiaries coupled with a real lack of other options for the Congress to control the explosive cost growth of this program that occurred in the 1970's -- and lack of such management options really means lack of good research and creative thinking.

Absence of informed debate of public disability policy issues continues today. For example, re-authorization of "The Rehabilitation Act," the key federal legislation creating many disability service and research programs and establishing disabled persons' "civil rights," is presently under consideration by the Congress (as H.R. 4021). Apart from testimony presented at Congressional hearings, there has been little published or oral commentary on this bill -- despite its many controversial provisions -- and so what scrutiny has occurred really amounts to "debate by rumor."

The Center will also be unique in that much of its research will have a keen futures orientation and intended to "frame the debate" as to the important

national disability policy issues from this perspective. Illustrating this approach is enclosed the Center's first "research prospectus" (or research problem statement) which describes the rationale for a study of "the future of public employment assistance to disabled Americans through the year 2000." To my knowledge, it is the only future-oriented evaluation of any federal disability effort either planned or underway of this scope in the United States.

Although futures research routinely figures into many public debates and actions -- from the environment to energy to agriculture to national economic performance to military weapons systems for the 1990's -- little "future thinking" is done about disability. Yet it is absolutely essential if we are to manage public policy wisely to avert a "coming disability crisis" and to avoid the lament of one disability expert that "we continue to plan for yesterday to overcome the deficits of a decade ago." The basis of this crisis is the costs associated with a large projected increase in the number of Americans with disabilities -- costs for providing an income to those who cannot work, for medical care, and for other service -- and which will be borne by government, business, and disabled persons and their families. The disabled population began expanding in earnest in the mid-1960's, and this growth is forecasted to continue for the foreseeable future, surely into the middle of the next century -- another (but largely unrecognized) consequence of the "aging" of the American population.

Other proposals to be developed by the Center shortly include studies of: poverty, homelessness, and hunger among disabled persons and their families, disability protection as an employee fringe benefit, medical care for disabled persons (including the impact of a large forecasted increase in the amount of the nation's medical care provided by HMO's), science and technology for the handicapped (federal disability science policy), the changing nature of the rehabilitation professions, and the demographics of the future disabled population. These several projects (and others) are included under the omnibus title of "The Disability 2000 Survey," a broad exploration of the "future of disability" that again reflects a core interest of the Center.

For the founding grant, the Center requests $75,000. This money will be used to establish a proper office (currently using donated space), equip and furnish it, organize its support functions (e.g., accounting and legal), and provide modest research staff salaries and expenses for one year. A detailed budget is available.

Several substantive accomplishments are expected in the first year. One will be writing and submitting specific project proposals (as enclosed) to other public and private foundations for funding. Second, a book of short papers or essays on key disability policy issues will be written and published (under either the aegis of the Center or by a university or commercial press). The working title of this monograph is: "Inventing a Future for Disabled Americans: Policy Challenges for the Next 25 Years." No comparable work currently exists. In addition, in keeping with the Center's role as an "independent voice" fostering public discussion and debate of disability

policy issues, ar least several "occasional" article or papers on current disability topics (e.g., news events) will be written (e.g., as "op-ed" pieces) and one or two conferences or seminars on proposed disability legislation or other disability topics organized and held.

I hope the W.E. Kellogg Foundation finds this proposal of interest and would be pleased to supply endorsements and any further information. I look forward to hearing from you.

Thank you.

Sincerely,

R. Alexander Vachon, III
Executive Director

Enclosure

THE NATIONAL DISABILITY POLICY CENTER

2100 Connecticut Avenue, N.W., Suite 208 • Washington, D.C. 20008 • (202) 667-1193

RESEARCH PROSPECTUS

The Future of Public Employment Assistance to Disabled Americans through the Year 2000

The state-federal vocational rehabilitation program is the nation's key program to help people with work disabilities get a job. In 1985, this program had a federal budget of $1.1 billion (plus another 20% from the states) and assisted about 226,000 disabled persons to become "gainfully employed." It has proven a durable program for over 65 years and has the twin distinctions of being among the oldest continuing federal social programs and state-federal partnerships.

But today demographic, economic, political, and technological trends are rapidly re-shaping the environments of both public vocational rehabilitation (VR) and employment -- trends which include the "aging" of the American population (with a relative shrinkage in the size of the labor force and a projected 35% increase in the number of work disabled people by 2000), laws which have the effect of promoting private rehabilitation (e.g., mandatory worker's compensation rehabilitation statutes in some states), increasing population education levels, structural changes in the labor market (e.g., from industrial to service jobs), expanding purposes for public disability services (e.g., from a specific employment focus to "independent living"), and shifting patterns of disabling conditions (e.g., infectious to chronic).

These trends have already had direct effect on VR, e.g., today's clients are very different from those for whom the program was originally designed and there has been a surge in private rehabilitation vendors. But little research has been done to determine how well the state-federal program has responded to changing conditions, and how it must adapt to remain successful in the future.

There is also evidence that the total national effort for employment assistance to work disabled persons (the state-federal program plus all other public and private aid) is not adequate. At present, about 59% of working age disabled Americans are jobless. This joblessness has serious consequences for both disabled persons and their families: about 26% of disabled persons live below the poverty line, and another large percentage are "near poor." (Conversely, it appears that between 30 and 70% of all poverty in the United States can be traced to disability). A second purpose of this research is to critically examine our public goals and strategies -- that is, the planning process itself -- for employment assistance to disabled persons and recommend measures to improve the performance of this "disability system."

This research is expected to have diverse, profound implications for: re-thinking the organization of federal and state rehabilitation agencies, the training, certification, and career paths of rehabilitation counselors and administrators, proposals for new VR services (e.g., job placement) and program development strategies (including perhaps expansion of the federal Rehabilitation Diffusion Network), private industry - public VR cooperation, and the quality of disability policy research and scholarship.

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