REPORT OF THE NATIONAL CONFERENCE ON INDEPENDENT LIVING SERVICE REGULATIONS PER P.L. 95-602

March 7-9, 1979
Sheraton National Hotel
ington, Virginia

Prepared by Gerben DeJong

Medical Rehabilitation Research and
Training Center Number Seven
Tufts-New England Medical Center
Boston, Massachusetts

REPORT OF THE NATIONAL CONFERENCE ON INDEPENDENT LIVING SERVICE REGULATIONS PER P.L. 95-602

March 7-9, 1979
Sheraton National Hotel
Arlington, Virginia

Prepared
by
Gerben DeJong

Medical Rehabilitation Research & Training Center No. 7
Tufts-New England Medical Center
Boston, Massachusetts

Cosponsored with the
Rehabilitation Services Administration
U.S. Department of Health, Education, & Welfare

The production of this report was supported with funds provided by the Rehabilitation Services Administration, Office of Human Development, U.S. Department of Health Education and Welfare (Grant No. 16-P-57856/1-05)

ACKNOWLEDGEMENTS

The National Conference on Independent Living Services Regulations was co-sponsored by the Rehabilitation Services Administration (RSA) and the Medical Rehabilitation Research and Training Center of Tufts-New England Medical Center in Boston. While the conference was made possible through a grant from RSA to the Tufts program, the planning and implementation of the conference was very much a joint effort between the two organizations.

Special credit goes to Robert Humphreys, Commissioner of RSA, who saw the need for a consumer viewpoint in the regulatory process. The Commissioner's commitment to consumer involvement and his initiative in launching the conference bode well for the implementation of P.L. 95-602.

The conference was planned and implemented in the space of about five weeks. Such a task could not have been completed without the timely assistance of many individuals. Bill Bean, who took the lead role on behalf of RSA, doggedly and effectively mobilized the resources of his agency. The success of the conference can in large measure be attributed to Bill Bean's persistence and tenacious attention to details. He was well assisted by individuals such as Dick Melia, Peter McCabe, Delorise Anderson, Allen Menefee, Christine Tansey, and others. Joe Fenton of RSA's special centers program deserves recognition for his role in making the grant award possible. A more complete listing of contributing staff can be found in Appendix E of this report.

On the Tufts side, Ruth House and Susan Dailey handled conference logistics and attended to the well-being of conference participants. Their role was indispensable. Their diligent efforts in attending to the remotest detail allowed the conference to proceed without hitch. Susan Dailey was responsible for the typing of this manuscript and other written products.

Fred Fay, The Center's research director at Tufts, provided spirited leadership that extended to all phases of the conference-from conference planning to the final plenary session. Fred Fay's long-standing commitment to consumer involvement helped to launch Tufts' role in the conference. His invaluable encouragement and critical review is hereby acknowledged.

Janet Minch and Barry Goldsmith of Tufts' consumer involvement unit offered their insight into the consumer involvement process and unhesitantly provided back-up services whenever needed.

Gerben DeJong, of Tufts' independent living research program prepared the conference agenda and structured the conference proceedings and workshops. He was also responsible for the sorting of conference testimony and the preparation of this report.

The conference could not have succeeded without the able direction provided by the various workshop discussion leaders. Never have a group of individuals so willingly taken on a significant role on so short notice. This report would not have been possible without their contributions in summarizing the suggestions and recommendations emanating from the various workshops. Each workshop leader was well assisted by workshop recorders/cofacilitators made available from the ranks of RSA staff. A listing of the workshop leaders and recorders can be found in Appendix C of this report.

A remarkable feature of the conference and the planning effort was the willingness of so many to join ranks in meeting a common objective. The common commitments expressed at the conference promise to carry forth into the eventual implementation of the independent living provisions authorized in P.L. 95-602.

Gerben DeJong
Boston, Massachusetts
May 14, 1979

NOTE

This report draws mainly from materials prepared by workshop leaders and from transcripts of summaries presented on the last day of the conference. To assure accuracy, the text of this report was reviewed by each workshop leader and revised accordingly.

The main text of this report is preceded by a list of conference recommendations regarding the forthcoming independent living services regulations. This list is intended to be a checklist by which proposed regulations and future programs can be evaluated.

Because this report and its recommendations often refer to specific sections of the legislation, relevant portions of the statute are included in Appendix A for easy reference.

It is difficult to condense numerous discussions involving many individuals to a concise set of recommendations. Conferees did not vote on specific recommendations. However, there was a remarkable consensus on almost all issues. This report attempts to document that consensus. Moreover, the report attempts to make the recommendations as explicit and specific as possible in order to more effectively communicate the conference's message to regulation writers and policy makers at all levels.

TABLE OF CONTENTS

CONFERENCE RECOMMENDATIONS

Recommendations Regarding Eligibility

1. RSA should avoid narrow categorical requirements in establishing eligibility for independent living services.
2. When funds are limited, priorities for receipt of independent living services should be left to the states to express in their state plan.
3. Persons should not be made ineligible for Title VII services just because a person was eligible for an unrelated Title I service.
4. First priority for independent living services should be given to those not served under any other provisions of the Act. Second priority should be given to those underserved by other portions of the Act.
5. No upper or lower age limits should be set in the regulations in determining eligibility.
6. Regulations should not attempt to define "significant improvement" as provided in Sec. 702 (a). Nor should benefits be terminated when there is no "significant improvement." Regulatory language should be developed to prevent an untimely withdrawal of services that would reduce a person's ability to live independently.
7. Regulations should permit states to establish sliding fee schedules provided that (1) they are realistic, and (2) they do not create any new disincentives to employment.
8. The eligibility determination process should be kept short and simple especially when only one or a few services are needed. A simplified IWRP could serve as the eligibility determination document.
9. The responsibility for determining eligibility should rest with the designated state unit but providers should be allowed to decide whether a person is ready for their services.

Recommendations Regarding Maintenance of Effort

10. To maintain state effort under Title I, the regulations should specify that upon initial application for services a person is presumed to have a vocational goal, and that a person is to remain eligible for Title I services until the possibility of the vocational goal is exhausted.
11. States should be permitted to develop a single IWRP for both vocational rehabilitation and independent living services; and further, that the IWRP simply be amended should there be a change in goals.
12. Regulations should require that interagency agreements be initiated at both the federal and state level to insure maintenance of effort by other human service programs.
13. The regulations should contain a preamble making clear that Title VII is not to be used to refinance services now available under other programs.

Recommendations Regarding State Plan

14. To insure rapid implementation, the state plan should, during the first year only, be a simplified preprinted document enabling states to comply with a number of statutory assurances.
15. Regulations regarding the state plan should encourage states, whenever possible, to rely on existing studies rather than initiate new studies in determining how it should provide independent living services.
16. With regard to the state plan, regulations should define technical assistance to include outreach activities to identify indigenous persons and groups needing assistance in matters such as developing proposals and organizing structures to provide independent living services.

17. Regulations should require that, in having a "substantial role" in developing the state plan, handicapped individuals have more than an advisory role but a policy making role as well.

18. Handicapped persons should be involved in all phases of the state plan including the preparation of any special studies and the monitoring of the plan's implementation.

19. Gubernatorial review of the state plan for independent living should not be a regulatory requirement.

20. A state's request for a waiver of the minimum 20-percent set aside under Part A should be granted for only one year at a time. The regulations should carefully spell out the criteria needed for a waiver and that a waiver be granted only after the state has taken specific steps to advertise, to solicit proposals, and to make technical assistance available. Once requested, states should be required to work with consumer groups to assume that no waiver be needed in following years.

21. Each state plan should give assurances that individuals will have the right to review and, if necessary, appeal the service plan outlined in the IWRP.

22. Regulations should indicate the types and sources of state match needed for federal funding.

Recommendations Regarding Centers for Independent Living

23. A consumer-based committee or group should be established at the state level to review applications and proposals for Part B funding. This panel may be the same group charged to develop and review the state plan.

24. Consumer groups applying for Part B funding should have the right to appeal their applications directly to RSA if it could be demonstrated that the proposal was rejected for reasons not in keeping with the state plan or federal regulations.

25. Regulations should indicate that states must submit an **acceptable** application for Part B funding to meet the 6-month deadline in Sec. 711(d). The mere submission of an application is not sufficient.

26. Regulations should allow a state to announce its intention not to participate in Part B in any year to allow RSA to immediately entertain applications from local sources without waiting 6 months.

27. The absence of a state plan within the designated 6-month period should signal RSA to begin accepting applications from local sources.

28. States could be granted waivers for good cause if a state plan was not developed in the allotted amount of time to qualify for Part B funding.

29. The regulations should spell out the distinction between a comprehensive rehabilitation center and an independent living center.

30. Since independent living centers, unlike comprehensive rehabilitation centers, are required to have substantial consumer participation, an independent living center may become a comprehensive rehabilitation center but not the reverse.

31. "Substantial involvement" in the policy direction of an independent living center should be defined in the regulations to mean that **at least** a majority of those on the board of directors (or similar policy making group) be handicapped persons. States may increase that requirement but not decrease it.

32. Substantial involvement in the management and employment of an independent living center should also be defined to mean that a majority of those in management and other positions be handicapped persons. However, this requirement may be waived only during the early years of a center's existence if the center could demonstrate that it had/has a strong affirmative action plan to locate and train handicapped managers and employees.

33. The regulations should point out that majority involvement of a single disability in the management and direction of an independent living center does not constitute substantial involvement. Regulations should indicate that centers geared to the needs of a single disability are not eligible for Part B funding.

34. Regulations should single out users of independent living services as one special group of handicapped persons to be included on the boards or policy making panels of independent living centers.

35. IWRPs should not be required for individuals seeking a single Part B funded service. However, a simplified IWRP or similar document should be developed for individuals seeking comprehensive independent living services under Part B.

36. Any communication written or otherwise-to which the disabled person is entitled such as an IWRP---should be prepared in the communication medium required by the disabled individual, e.g., braille or interpreters.

Recommendations Regarding Funding & Accountability

37. In disbursing Part A funds set aside for local public and nonprofit organizations, states should solicit requests for proposals making clear the criteria for an acceptable application.

38. In disbursing the Part A set-aside, states should make technical assistance available to fledging organizations to help them qualify for funding.

39. The majority of the state panel reviewing grant applications under the Part A set-aside should be comprised of consumers representing various disabilities. The consumer panel should also be empowered to monitor and evaluate programs receiving funds under the Part A set-aside.

40. To be eligible for funding under the Part A set-aside, recipient organizations must have majority consumer participation on their policy making boards.

41. Regulations and fiscal guidelines should permit sufficient flexibility to allow expenditures to shift from one service to another depending on the special needs of the consumer population.

42. The status 26 closure system now used in vocational rehabilitation should not be used as the method for determining the efficacy of independent living services. New methods should be developed to evaluate the effectiveness of independent living services.

43. Consumers should be involved in all phases of the evaluation process – in developing the evaluation plan, in constructing evaluation measures and in analyzing the results.

Introduction/Purpose of Report

On November 6, 1978, President Carter signed into law, P.L. 95-602, the Rehabilitation, Comprehensive Services and Developmental Disabilities Amendments of 1978. P.L. 95-602 establishes a new Title VII which provides for a three-part program in independent living.[1]

In preparing regulations to implement the new independent living provisions, the Rehabilitation Services Administration (RSA) has actively sought the advice of numerous groups, organizations, and individuals concerned with independent living. Unfortunately, consumers of rehabilitation services are often not adequately represented when policy decisions and regulations are made. To assure greater consumer involvement in the development of new regulations, the Commissioner of Rehabilitation Services agreed to set aside funds for a national conference addressing the development of independent living service regulations. The purpose of the conference was to advise RSA on how it might best use its regulatory powers in implementing the new Title VII.

The National Conference on Independent Living Services Regulations was held March 7, 8, and 9 at the Sheraton National Hotel in Arlington, Virginia. The conference was co-sponsored by the Rehabilitation Services Administration and the Medical Rehabilitation Research and Training Center of Tufts-New England Medical Center in Boston. Some 55 consumers and 20 attendants, and a variety of other independent living advocates came to participate. The various participants represented a large cross-section of disabilities—deafness, blindness, spinal cord injury, post polio, cerebral palsy, mental retardation, epilepsy, autism, and others. The conference was augmented by the presence of key RSA staff who observed the proceedings and assisted in the logistics.

The purpose of this report is to summarize the conference proceedings and to communicate to RSA how it might best implement the new independent living provisions of P.L. 95-602 through the promulgation of regulations. Like the conference, this report is organized around the 5 workshop topics:[2]

I. Eligibility
II. Maintenance of Effort
III. State Plan
IV. Centers for Independent Living
V. Funding and Accountability

Each conferee attended a workshop on each of the 5 topics. Conference participants were organized into 8 groups. Altogether, some 40 workshop sessions were held. Each workshop topic was led by a discussion leader who was assisted by a RSA staff person. (A list of discussion leaders and RSA cofacilitators can be found in Appendix C of this report). The content of this report draws mainly from the materials prepared by workshop leaders and their cofacilitators and from transcripts of summaries presented on the last day of the conference.

This report is being issued prior to the publication of proposed independent living regulations in the **Federal Register.** Proposed regulations are expected to be published in June 1979. Since the national conference was held well before the forthcoming publication of proposed regulations, this report does not comment directly on these regulations. (Occasional references are made to earlier versions of the regulations.) However, this report does serve as a consumer benchmark by which forthcoming regulations can be evaluated.

[1] Part A authorizes a comprehensive independent living services program to be administered by the state vocational rehabilitation agency to meet the needs of disabled persons who may not qualify for traditional vocational rehabilitation services. Part B authorizes a grant program for independent living centers. Part C authorizes independent living services for older blind persons

[2] A list of the questions addressed in the 5 workshops can be found in Appendix B.

I
Issues Relating to Eligibility

Who Should be Eligible

Section 702 of the new Act defines who is eligible for independent living services. In general, this section of the Act appears to say that independent living services are intended for those individuals not receiving traditional vocational rehabilitation services because of the severity of their disability. However, a large number of eligibility issues remain to be resolved in the regulations.

The overwhelming sense of the conference was that narrow categories of individuals should be avoided for purposes of determining eligibility. Too many consumers have experienced the pitfalls of narrow categorical requirements in other programs. These requirements have often precluded individuals from receiving needed services when seeking greater independence.

Nonetheless, even at authorized funding levels it is doubtful that all who apply for independent living services can be accommodated to the full extent of their need. Some priorities will have to be set as to who will be served. Conferees noted that if priorities have to be set, that they be expressed in the form of guidelines or in the state plan. It was felt that regulatory language has a peculiar staying power that may perpetuate categorization beyond the time absolutely needed. States vary in the degree to which independent living services are available. Many conferees felt that the needs of individual states would be better taken into account if priority setting was relegated to the state plan.

Conceptually, a distinction could be made between (1) being eligible and (2) receiving services. While the regulations should define eligibility broadly as required in the law, this does not preclude a state plan from spelling out who will be served first when resources are limited.

Section 702 states that "priority of services under this part shall be given to individuals not served by other provisions of this Act." Technically, a person receiving a particular service under Title I, for example, could be precluded from any services under Title VII. Conferees felt that persons should not be ineligible for Title VII services just because a person was eligible for an unrelated Title I service. Title I recipients should be eligible for Title VII services as long as there is no duplication.

For the most part, conferees agreed that first priority for services be given to those not served under any other provision of the Act and that second priority be given to those not adequately served by other portions of the Act.[3]

Conferees also concluded that the regulations should remain silent on the matter of age--there should be no upper or lower age limit for services. While it may be desirable to target services toward selected age groups, there is no statutory basis for making age an eligibility criterion.

The Act implies that services are to be rendered to those who have the potential "to improve significantly either his ability to engage in employment or his ability to function independently in his family or community" (Sec. 702(a)). The various groups found it difficult to operationalize the concept of potential or to define "improve significantly." Such concepts and definitions make the eligibility determination process messy. They encourage "creaming" based on very subjective notions of what constitutes potential for improvement. Conferees addressing this issue felt that the regulations should not attempt to define significant improvement. No regulatory language could adequately deal with the issue of potential for improvement without adding new difficulties and new barriers toward independent living.

A closely related issue is whether the Act implies that services be terminated if there is no "significant improvement." Conferees were uniformly opposed to a termination of benefits if there was no significant improvement. For example, an individual may initially achieve greater independence as a result of services but may be unable to continue improving as he/she once did. While the continuation of services will not significantly improve a person's ability to live more independently, the withdrawal of services could significantly **reduce** a person's ability to live independently. All the discussion groups wanted language in the regulations that would

[3] One group addressed the issue of whether the Developmental Disabilities Amendments should be considered part of the Act and whether those receiving services under the developmental disability provisions should receive lower priority for independent living services. Various members of this group expressed the opinion that the regulations should incorporate Department of Health, Education, and Welfare's (HEW's) General Counsel ruling that the Developmental Disabilities Amendments are not part of the Act and should, therefore, not affect the issue of priorities and eligibility.

avoid Catch-22 situations where a person would be denied vital services after maintaining a stable level of independent living.

Instead, many of the groups urged that there be an indefinite provision of services in order to maintain "enhanced ability." Conferees felt that it was not the intent of the Act to allow individuals to regress because certain services were not available. Conference participants urged that regulatory language be developed that would prevent an untimely termination of services.

Some groups were opposed to any regulatory language that would make a person ineligible for independent living services because he or she has a medical condition that is "rapidly progressive or terminal."

Should Services be Means Tested

Conferees had mixed feelings about whether independent living services should be means tested, i.e., whether an individual's income and resources should be taken into account in determining eligibility for independent living services. However, there was a consensus that consumers of independent living services should pay for services if they could afford to do so. Regulations should permit states to establish sliding fee scales that adequately take into account the additional requirements and expenses facing a severely disabled person in our society. Regulations should prohibit any sliding scales that would make a person materially worse off as his/her income rose or that would create any disincentive to employment as is the case in other human service programs.

How Should Eligibility be Determined

In many human service programs, the eligibility determination process is cumbersome and lengthy. There was a nagging feeling among conference participants that an exhaustive eligibility determination process would leave precious few dollars for services. Participants cited potential incidents where a person might only need a single specific service. An elaborate evaluation protocol should not be required when only one specific service is needed.

Several of the groups felt that the Individualized Written Rehabilitation Plan (IWRP) could serve as the basic eligibility determination document. However, the IWRP should be kept short and simple and not require documentation that is out of proportion to the services needed. By using the IWRP, eligibility would be based mainly on the services needed, not on other peripheral matters.

The responsibility for determining eligibility should rest with the designated state unit but providers should decide which persons are eligible for their services. For example, a state agency may determine that a person is eligible for attendant care but a provider agency may have to evaluate whether an individual is ready to assume the responsibilities of directing an attendant.

One of the more perplexing eligibility issues was how eligibility determination for Title VII services might be coordinated with eligibility determination for Title I vocational rehabilitation services. While priority for Title VII services are to be given to those not served under Title I, there remains the problem of determining where the eligibility determination process for Title I ends and the eligibility determination process for Title VII begins. One group thought that the denial of Title I eligibility should automatically make an individual eligible for Title VII services. Other groups rejected this position. Some felt that, at the very least, a person turned down for Title I services should be informed of the Title VII program and how to apply. Most felt that there should be separate eligibility determinations for each program but that the determinations should be coordinated. Eligibility coordination is especially needed for those individuals who may qualify for different services under both titles of the Act.

II
Maintenance of Effort

The new Title VII authorizes a variety of services that are to some degree available under other programs such as Title I (vocational rehabilitation) under the Rehabilitation Act, and Title XIX (Medicaid) and XX (Social Services) under the Social Security Act. States may be tempted to refinance existing services with Title VII leaving little or no increase in services. The

issue at hand is what maintenance-of-effort language should be drafted into the regulations.

The House Committee Report on H.R. 12467[4] makes clear that the independent living services program "is designed to be an adjunct to the existing program of rehabilitation services" (p.28). The statute also makes clear (Sec. 701) that Title VII is "supplementary to grants for vocational rehabilitation services under Title I."

The statute and committee reports are less clear as to what maintenance of effort there should be with respect to non-rehabilitation programs that also affect the ability of an individual to live independently. The House Committee Report (p.29) acknowledges the need "to coordinate the delivery of comprehensive independent living services including special education, vocational rehabilitation, public assistance, medical assistance, social services, and comprehensive health and mental health." The report indicates that section 101 of the Act directs state rehabilitation agencies "to seek benefits and services available through other Federal programs." The fact that this statutory authority is referenced with regard to the provision of independent living services, it appears that it was the intent of Congress that needed benefits relating to independent living be sought from other federal benefit programs whenever possible.

Maintaining Effort under Title I and Relationship of Title VII to State Vocational Rehabilitation Programs

As noted above, the statute requires that Title VII services be supplemental to Title I services. In other words, Title VII funds should only be used if a person is unable to obtain services under Title I. To confuse matters somewhat, the statute defines comprehensive services for independent living to include "any appropriate vocational rehabilitation service" as defined under Title I (Sec. 702). Moreover, independent living services may be rendered to "secure and maintain appropriate employment" (Sec. 702).

Thus, on the one hand, Title VII is targeted to those for whom employment is not an obtainable goal, and on the other hand, Title VII is available to those who wish to "secure and maintain employment." Simply stated: Where does Title I end and Title VII begin?

In general, conference participants were of the opinion that Title I services should continue to be made available until the possibility of a vocational goal had been exhausted. Conference participants felt that if a vocational goal was presumed not to exist, such a presumption would result in an unnecessary raid on limited Title VII funds. They felt that the present vocational rehabilitation system should be stretched, as is now done in some instances, to meet the independent living goals of severely impaired persons whenever possible.

Some conferees were concerned that Title VII might become a new "dumping ground" for more difficult cases. They cited the ever present tendency of the system to "cream" the easier cases that result in quick and successful closures. These conferees felt that Title VII should not cause vocational rehabilitation counselors to relax the vocational objective however remote the objective may at times appear. Persons should be directed to achieving their maximum potential.

Conference participants were concerned that important life-sustaining services might be disrupted as individual eligibility shifted from one title to another. The conference was divided as to how this problem could be avoided. Service disruption can be minimized if independent living services are integrated with vocational rehabilitation services and other service systems. Others disagreed. Some felt that there already was too much disruption and untimeliness of services within the vocational rehabilitation system. Moreover, the counselor role is often in conflict with the goal of self-direction implicit in independent living.

The problem of service disruption and service coordination between Titles I and VII speaks to the larger issue of administration of independent living services. To what extent should independent living services be integrated/consolidated with traditional vocational rehabilitation services? Should the administration of independent living be separate from vocational rehabilitation services? On this issue there was no clear consensus. But, conference participants did echo a strong distrust of the vocational rehabilitation system. Their distrust was often based on many personal encounters with the system. As a whole, conferees were skeptical of administrative integration but at the same time mindful that the lack of administrative integration also posed new hazards.

[4] H.R. 12467 was the House version of P.L. 95-602.

The upshot of the matter for purposes of regulation writing is that the states should be given flexibility in how they wish to administer independent living services under Part A. The regulations should not be too prescriptive until various state experiences can be evaluated in the years to come.

One method of achieving service coordination and maintenance of effort is to presume, as suggested earlier, that a person is eligible for Title I vocational rehabilitation services unless evaluated otherwise at a later time. This would allow the use of Title I funds for diagnostic work and some of the initial administrative costs. The costs of initiating an individualized written rehabilitation plan (IWRP) would be borne by Title I.

Under this approach, a person could begin to receive Title VII services without disruption when exiting from the Title I program for any one of several reasons -- change in goal, met vocational goal, terminated unsuccessfully, etc. The delivery and payment of Title VII services could be initiated by simply changing the goal specified in the IWRP. Thus, one amended IWRP instead of two IWRP's would be required. In some instances a person might require services under both Titles I and VII. In such cases it would make little sense to write up two IWRP's. A single IWRP, specifying both independent living and vocational goals, would be preferred. However, given the latitude of Title I services and purchase methods, clients should continue to receive services under Title I whenever possible without expending Title VII funds.

Suggestions of this kind appeared in one form or another in several of the workshop sessions. Implicit in these suggestions is a recommendation that the regulations permit states to develop a single IWRP for both vocational and independent living goals; and further, that the IWRP simply be amended should there be a change in goals. Moreover, the regulations should specify, that upon initial applications for services, a person is presumed to have a vocational goal.

These recommendations would resolve several major issues relating to maintenance of effort and service coordination between Titles I and VII. It would:

* Shift much of the initial administrative costs—eligibility determination and evaluation—to the Title I program.

* Reduce administrative costs by avoiding needless duplication in paperwork; allow for one initial evaluation of service need.

* Provide for a more timely and coordinated delivery of services.

Maintaining Effort Under Other Human Service Programs

Many other benefits also enable a disabled person to live independently--medical care, housing, attendant care, and others. These benefits and services are generally available from sources outside the vocational rehabilitation system. The conference was not able to give sufficient attention to the role of these different service programs. However, one theme was clear: these service programs must maintain their current levels of effort. Title VII monies should not be used to refinance existing programs outside the vocational rehabilitation program.

While not directly required by statute, conferees strongly recommended the use of interagency agreements at the federal and state levels to insure adequate maintenance of effort by other human service programs. Interagency agreements are required under the Title I program (Sec. 101 (a) (11)). As mentioned earlier, the House Committee Report (p. 29) refers to this authority with regard to maintaining effort in the area of independent living. Thus, it would appear that it was the intent of Congress that similar interagency efforts be undertaken in the provision of independent living services. Regulatory language should be drafted to reflect this intent.

Conference participants recommended that the regulations contain a preamble making clear that Title VII is not to be used to refinance services now available under other programs. The regulations should spell out that Title VII is a "last dollar" program.

III
State Plan

In addition to the statute and regulations, the state plan is an important vehicle for shaping the scope and character of independent living services in a given state. The statute (Sec. 705) requires each state to submit a three-year state plan in order to be eligible for independent living funds. The statute provides that the state plan contain certain assurances but leaves considerable discretion to RSA: "Each such plan shall. . . contain such other information, and be submitted in such form in accordance with such procedures, as the Commissioner may require" (Sec. 705 (a) (9)).

How Extensive

The most elementary state plan would consist of little more than a federally prescribed compliance checklist. A more sophisticated state plan might consist of a comprehensive blueprint for the development and provision of independent living services.

Conference participants did express some definite thoughts as to how extensive the state plan should be. Participants suggested that, for the first year only, an interim preprinted format should be designed as a method of getting the states to comply with a number of statutory assurances. A simplified interim approach would allow states to acquire first-year funding without delay. Moreover, since initial appropriations are likely to be limited, conference participants were hesitant to recommend state plans whose scope would be out of proportion to the funds and services available.

The three-year plan required by statute would be more extensive. But even with the three-year plan, the mood of the conferees was cautious. The statute provides that the state study and consider various ways of delivering independent living services. Conferees were concerned that too many independent living monies might go toward studies rather than services. Instead, states should, whenever possible, rely on studies already completed.

Consolidated State Plans

In general, conferees did not support the concept of a consolidated state plan--where the state plan for independent living would be consolidated with the state plan for vocational rehabilitation or the state plan for developmental disabilities. A preliminary draft of the regulations for independent living (Sec. 1363.2(c)) would permit consolidation. While consolidation might facilitate coordination of services between various rehabilitation programs, conferees feared that independent living services would lose the visibility they need especially during the growing years of the program. The relatively small size of the independent living rehabilitation program would be dwarfed by its vocational rehabilitation counterpart. Consolidation of state plans is not required by statute.

Technical Assistance

The authors of P.L. 95-602 were concerned about the inability of poverty areas to compete on an equal footing in acquiring funds and services. Thus, the statute provides that the state plan contain "assurances that special efforts will be undertaken to provide technical assistance to urban and rural poverty areas" (Sec. 705 (a) (6)). The various discussion groups felt that technical assistance would not be meaningful unless individuals and organizations could be identified as potential recipients of technical assistance. Accordingly, regulations should define technical assistance to include outreach activities designed to locate indigenous individuals and groups who could benefit from technical assistance in matters such as developing proposals and organizing structures to provide independent living services.

Consumer Involvement

By far, the issue most discussed with regard to state plan development was the role of consumers. The state plan by statute is to "provide assurances that handicapped individuals shall have a substantial role in developing the state plan" (Sec. 705(a)(7)). The consensus of the conference was that having a "substantial role" meant going beyond an advisory role and establishing a policy making role as well

No clear statement emerged from the conference as to how a policy making role should materialize. However, workshop discussions often presumed the existence of some group or council that would develop and pass judgement on the state plan for independent living. Some felt strongly that members of such a group or council not be selected by the controlling state agency but through a self-selection process. Exactly how such a self-selection process would work was left unspecified.

Conference participants urged that disabled persons be involved at all stages of the state plan's development beginning with any special studies that might be conducted. Participants suggested that consumers be involved by holding public meetings or hearings both prior to, and after, the development of the state plan. It was also suggested that a progress report, prepared by a consumer advisory board, be required and submitted with the annual update of the state plan..

Gubernatorial Review

An early draft of the regulations provides that the state's governor be given a 45-day period to review the state plan for independent living (Sec. 1363.3). Conferees felt that such a requirement would add unnecessary delay to the implementation of the state plan. The right of review is inherent in the office of the governor and should not be made mandatory by regulation.[4]

Waiver Authority

According to statute, the state plan is to assure that at least 20 percent of funds received by a state for Part A services be "used to make grants to local public and private nonprofit organizations for. . . independent living services" (Sec. 705(a)(8)). However, a state may seek a waiver of this requirement if local agencies are not available to provide independent living services. Conferees recommended that the waiver request should be an annual one. Once a waiver has been requested, the state agency should contact all consumer groups and work with them in an effort to stimulate organizational growth and to assure that no waiver need be requested in following years.

Overlooked Issues

Various participants were concerned that the preliminary draft of regulations regarding the state plan had overlooked a number of important issues. Two examples are noted here. First, there is a need for each state plan to give assurances that individuals will have the right to review and, if necessary, appeal the service plan outlined in the IWRP. And second, there is a need for each state plan to specify how the state will meet the federal matching requirements. Regulations need to indicate what types and sources of state match will be acceptable, e.g., whether the match can be in kind as well as in cash.

Overall

Overall, conference participants were very much aware that the state plan is an important document directing the delivery of independent living services. The role of the consumer was judged to be critical. However, conference participants were apprehensive that the extensive effort to stimulate consumer involvement would be a hollow one if there were insufficient appropriations to give the state plan any substance in the form of services.

[4] If this section were to remain in the regulations, many felt that the consumer board on policy council should be given the same rights of review as the governor would have.

IV
Centers for Independent Living

Centers for independent living have come to be viewed as an important model for the provision of independent living services. Centers typically tend to be consumer-controlled and thus help to foster the self-determination goals of disabled persons. By establishing a separate Part B under Title VII, the statute tacitly recognizes the importance of independent living centers in meeting the needs of disabled persons.

Relationship to "Designated State Unit"

The law is somewhat schizophrenic. On the one hand, it insists that centers for independent living be consumer-directed; on the other hand, it makes the "designated state unit" (the state vocational rehabilitation agency, the principal grantee agency under Part B. Both the House and Senate Committee reports expressed considerable confidence in the ability of state vocational rehabilitation agencies to administer the new independent living provisions. However, state agency direction is likely to conflict with the consumer direction goals of centers for independent living.

To overcome this potential conflict between agency and consumer goals, conference participants suggested that a consumer-based committee or group be established at the state level to review applications and proposals from various centers for Part B funding. This group or committee might be the same body charged with reviewing the state plan. In fact, the statute (Sec. 705 (a) (3) (A)) requires that the state plan include a description of the state's goals and plans with respect to the distribution of Part B funds. Some conference participants felt that duplication of effort would be reduced by having one body review both the state plan and the proposals from various parties seeking Part B funding. [6,7]

Many felt that a consumer group applying for Part B funding from the state agency should have the right to appeal their applications directly to RSA if it could be demonstrated that the proposal was rejected for reasons not in keeping with the state plan or federal regulations. Some individuals felt that state agencies might, in some instances, not be sufficiently responsive to the independent living aspirations of disabled persons. However, the existence of a consumer-based review panel should minimize the occurrence of such appeals.

According to statute (Sec. 711(d)), centers for independent living can apply directly to RSA for Part B funds if the designated state unit has not submitted an application within six months from the time the commissioner (of RSA) begins to accept such applications. Conference participants suggested that the regulations should interpret this statutory provision to mean that if the commissioner has not received an *acceptable* application within six months, the commissioner may accept proposals from other applicants. Conference participants also suggested that the regulations should allow a state to announce its intention not to participate in Part B in any one year so that RSA can move immediately to entertain applications from various centers or other organizations without waiting six months.

Consumer participants also suggested that the absence of a state plan (which must include the state's intentions with respect to Part B) should also satisfy the requirements of Sec. 711 (d), that is, allow RSA to accept applications from sources other than the designated state unit before waiting the full six months. Participants did add a few qualifications. If a state was in the process of actively developing a state plan, but had not completed it in the allotted time, extentions or waivers could be granted for good cause. Participants feared that "many states might develop a state plan for the sake of developing a plan without sufficient consumer input." Without consumer input, "a plan can be developed quickly."

A minority felt that "if a state did not write a plan and did not apply for independent living program monies, that perhaps a sanction should be applied in the regulations." The strongest

[6] One group, in discussing the "20-percent set-aside" under Part A (see next discussion on funding and accountability), felt strongly that the group developing the state plan should definitely not be the body reviewing grant applications from nonprofit organizations such as centers for independent living.

[7] An issue marginally addressed by the conference is the matter of conflict of interest. It is likely that persons applying for funds under Part B on behalf of a local group may also be on the panel receiving proposals. Regulations should prohibit such conflict of interest and provide procedures to avoid such problems.

sanction would be to withhold money. "That always does something to people." But such sanctions can also backfire: If a state merely wrote a plan to keep itself from being sanctioned, poorly planned services might result. Under such circumstances it would be better to avoid sanctions and to allow consumer groups to merely apply directly to RSA for Part B monies. Consumer groups have both the interest and determination to make good use of such funds.

Relationship to Comprehensive Rehabilitation Centers

Section 305 of the statute authorizes the development of comprehensive rehabilitation centers. These centers are to render a broad range of services similar to services rendered by independent living centers under section 711. What should be the relationship between these types of centers? Can a center be both an independent living center and a comprehensive rehabilitation center and receive funds under both Titles III and VII? The various workshops had difficulty answering these questions because the statute was not altogether clear as to the differences between these two types of centers. Participants suggested that the regulations should spell out the definitions of both types of centers. One noteworthy distinction, drawn directly from the Act, is that comprehensive rehabilitation centers do not require the same substantial consumer involvement expected of independent living centers. Based in part on this distinction, some felt that an independent living center could become a comprehensive rehabilitation center but not the reverse.

Consumer Involvement

Consumer involvement in independent living centers was one of the most discussed issues of the conference. Section 711 (c) provides "that handicapped individuals . . . be substantially involved in policy direction and management of such center, and . . . be employed by such center." "Substantial involvement" is not defined by statute but has been left to the regulation writers.

Most conference participants felt that, in the case of the more typical nonprofit center for independent living, substantial involvement should be defined in the regulations to mean that *at least* a majority of those on the board of directors (or similar policy making group) be handicapped persons. States could increase that requirement, but not decrease it.

Reactions were more mixed when it came to defining substantial involvement in management and employment. Some felt that simply being disabled did not make one a good manager or qualified for other employee roles. These individuals emphasized that there needed to be a strong affirmative action plan to locate and train potential managers and employees. According to this school of thinking, regulations should not require that a center, during its beginning stages, to have a majority of disabled persons in the management of its program.

Others felt strongly the other way. There were those who not only insisted that the majority of those in management be disabled but that the majority should be 80 or 90 percent.

A fair summary of the conference's feeling on this point is that the regulations should require majority consumer involvement in policy direction but should permit some flexibility in the areas of center management and employment especially during the early stages of a center's development.

Some felt that in focusing on percentages to define substantial involvement, an important point was being missed. Substantial involvement should mean the substantial involvement of *various* disabilities, not just one disability. A special concern was expressed in regards to states that have separated their designated state units based on disability. The concern was over separate designated state units developing separate state plans for separate independent living centers for separate disability groups. For example, there should not be a separate independent living center just for the blind. As one person expressed it during the summary session on the last day:

> I am not into segregation. I am into integration of all disabilities into the mainstream of society and that will happen in an independent living center where various disabilities are represented so that we can learn about the prejudices that we have about other disabilities and work them out in providing services.

The recommendation implicit here is that regulations should point out that majority involve-

ment of a single disability does not constitute substantial involvement and that centers geared solely to the needs of a single disability are not eligible for part B funding.

Who is a consumer or handicapped individual for purposes of defining "substantial involvement? Most groups defined consumer as an "individual who has used or can use independent living services." [8] Some of those representing the developmental disabilities wanted consumer to include "parent advocate, individual advocate, or advisor of a person who has used or could use the program." There was widespread concern as to whether such spokespersons could adequately represent the feelings and needs of disabled persons. The matter of parental involvement was particularly difficult. Some felt that the parents of nonself-directing individuals receiving independent living services should have a role, albeit a minor one, in the policy making procedures of an independent living center funded under Part B.

There was also an interesting comment or fear that some centers might use disabled people who are past or present employees and not select service users to serve on their boards. Thus, some wanted the regulations to single out users as a special group of handicapped persons to be included on boards or policy making panels. As one workshop leader summarized it," ...you can have different perspectives as a disabled person depending on what side of the table you are sitting or standing."

An important method of fostering consumer involvement has been the IWRP discussed earlier. The IWRP is now required for services under Title I and Part A services under Title VII. The question put to the conferees was whether an IWRP should also be required through regulation for Part B services, that is, services rendered by centers for independent living. There was a general consensus that if an individual came in for one service, such as attendant care or interpreter services, that person should not be subjected to a complete interrogation of his or her life history. But if an individual came in for comprehensive services, then a plan should be developed linking goals and services.

There was some disagreement as to whether a service plan developed by a center should be modeled after the IWRP now in use for vocational rehabilitation. Most felt that the traditional IWRP should be scrapped; others felt it should be retained for purposes of continuity and consistency.

One special recommendation did emerge from this discussion of IWRPs. It was recommended, by at least one group, that the regulations require "that any communication written or otherwise -- to which the disabled individual entitled, such as an IWRP -- should be prepared in the ... communication medium required by the disabled individual, e.g., braille, large print-type, interpreters, et cetera."

A Prevailing Concern

Centers for independent living are a special creature of the movement for independent living. Centers generally take on a number of characteristics consistent with the self-help philosophy. While public funding for centers have been eagerly sought, many are also aware that public funding can entail obligations--often in the name of accountability--that can compromise the self-help and advocacy functions of centers. Throughout the discussions on centers for independent living consumer participants were concerned that new requirements and regulations not compromise the self-help and advocacy goals of independent living centers.

V
Funding and Accountability

The subject matter of this workshop lacked the glamour of the others. The other topics -- such as eligibility, consumer involvement, centers for independent living -- are closer to the cutting edge of the independent living movement. Matters such as accountability and evaluation do not result in direct services, and in some instances, subtract from services. As indicated in the last section, accountability often entails paperwork and documentation that can quickly "bureaucratize" a consumer-directed service organization. Thus, some of the same skepticism about government funding that prevailed in other workshops was also very much in evidence in this last workshop on funding and accountability.

[8] The law does not refer to "consumers," only to "handicapped individuals." The question given to the workshops on centers for independent living asked: "Who are consumers?" In a sense, the question was the wrong one. The question should have read: Who are handicapped individuals?

Funding

The Act authorizes $80 million for independent living services in FY 1979; $150 million in FY 1980; $200 million in FY 1981; and "such sums" in FY 1982. Each state is to receive a minimum of $200,000 or one-third of 1 percent of the sums made available, whichever is greater. The Act does not give any direction as to how these sums or amounts appropriated should be distributed among the various parts of Title VII except that **no more than** 10 percent of the amounts appropriated may go to Part C – "Independent Living Services for Older Blind Individuals." Nor does the Act indicate whether the states, rather than the federal government, will decide how funds will be allocated among the various parts of Title VII.

The various discussion groups were asked how funds should be allocated among Parts A, B, and C and whether specific regulatory language was needed to insure appropriate allocations. Once again, the conference opted for flexibility insisting that the states needed latitude in allocating their funds in keeping with the varying needs of different states. Participants did feel strongly that a disproportionate amount of funds should go to centers supported under Part B. The various groups feared that if a disproportionate amount were channelled to Part A services, too many funds would be lost in maintaining the vocational rehabilitation agency charged with administering Part A services.

Conference participants looked askance at the special funding for Part C services for older blind persons. Even though the Act states that amounts "not in excess of 10 percent of the amounts made available" shall be allocated to Part C services, participants were wary of funding anything that approximated a special categorical program. In response, one spokesperson for the blind pointed out that Part C was originally an altogether different piece of legislation that was tacked on to Title VII as a matter of legislative convenience.

The Minimum 20-Percent Set-aside

As mentioned in our discussion on state plans, the law requires that states set aside at least 20 percent of the funds received under Part A to make grants for independent living services to local public agencies and nonprofit organizations (Sec. 705(a)(8)). Centers for independent living would be eligible for funding under this provision as well as under Part B. Some authorities believe that this provision may eventually become a more important source of funding for independent living centers than Part B.

Conference participants were asked how this set-aside might best be implemented. Many of the ideas advanced by the participants parallel the ideas suggested for the implementation of Part B funding for centers for independent living.

Some groups suggested that in disbursing the Part A set-aside, states should solicit requests for proposal (RFPs) spelling out the criteria for an acceptable application. The groups suggested that the availability of these funds should be advertised widely through the use of public notices or otherwise. In addition, the state should make technical assistance available to fledging independent living organizations in order to help them qualify for funding. The recommendation to make technical assistance available is very much in keeping with Sec. 705(a)(6) which requires that technical assistance be provided to urban and rural poverty areas.

Almost all the discussion groups recommended that the majority of the panel reviewing grant applications under the Part A set-aside should be comprised of consumers. The panel should have representation from across disabilities. The role of the panel would not be limited to reviewing grant applications but also monitor and evaluate programs receiving funds under the Part A set-aside. The groups also recommended that recipient organizations have majority consumer representation on their boards to be eligible for funding.

The minimum 20-percent set-aside may be waived if the Commissioner, meaning RSA, "determines on the basis of evidence submitted by the State, that such State cannot feasibly use the funds." Workshop participants recommended that the regulations carefully spell out the criteria needed to obtain the waiver. Participants felt that the state must take adequate steps to solicit proposals. Specifically, the regulations should require that a waiver be granted only after the state had taken specific steps to advertise, to solicit proposals, and to make technical assistance available. These recommendations are similar to the recommendations on waiver authority discussed in the workshops on the state plan.

Service Delivery

Conference participants were asked which Part A services should be provided directly by the state agency and which services should be rendered by a vendor agency. Most felt that client preference, service availability, and cost-effectiveness should be the guiding criteria. Some felt that state agencies should provide services such as counseling services and job placement since these are services they already provide. Most felt that state agencies should definitely not be in the business of providing advocacy services and peer counseling. Some distrusted the ability of state agencies to adequately render any of the independent living services listed in Sec. 702(b).

Conferees did not indicate any preference as to whether state agencies should purchase independent living services from vendors using grants, contracts, or fees for service. The general message was that there should be flexibility and that all three purchase-of-service methods should be used where appropriate. Conferees did express a concern about start-up costs and cash-flow problems. Many human service programs, are often financially behind before they start. Reimbursement for services is often delayed causing financial hardship. Conferees urged that these problems be taken into account which grants or contracts are awarded.

Fiscal Accountability

Participants did not see a need for fiscal controls beyond those commonly expected of human service organizations. Traditional accounting standards should be applied but fiscal guidelines and budgets should permit flexibility, allowing expenditures to shift from one service to another depending on the special needs of the consumer population. Independent living centers should have the flexibility to redirect their money without a lot of paperwork or explanation.

In vocational rehabilitation, total service costs are estimated for each case upon closure. The purpose of such a procedure is to monitor service expenditures and to measure the cost-effectiveness of services for different types of clients. This precedent prompted the question of whether expenditures under Parts A and B should also be made traceable to specific individuals. Seeing the red flag of paperwork, most participants felt that this would entail endless bookkeeping. In some instances, consumers of independent living services share services (e.g., interpreter services for groups of hearing impaired persons) making cost allocation difficult.

Evaluation of Service Effectiveness

The evaluation of service effectiveness is becoming increasingly important especially when continued funding is being sought. But how should service effectiveness and client/consumer progress be measured? Many participants spoke up against the status 26 closure system now used in vocational rehabilitation. Participant opposition to the accountability system used in vocational rehabilitation appeared to stem from two sources. First, the idea of getting "good closures" has resulted in "creaming" at the expense of more severely disabled persons who may require more services than a less disabled person. Second, the concept of closure suggests that there is some "end-point" or time when services are to be terminated. Unlike vocational rehabilitation services, independent living services may be required indefinitely.

Instead, participants urged that individual progress and services be evaluated relative to the goals and objectives stated in the IWRP or independent living service plan. Others suggested that the real issue is whether a consumer has become more "self-directed" as a result of independent living services. (No specific measures of self-direction were recommended.) Finally, still others suggested that the real measure of service effectiveness was whether consumers were satisfied with the services they received.

The upshot here is that new measures of service effectiveness are needed. The traditional measures used in vocational rehabilitation will not do. Participants were nonetheless acutely aware that the issue of cost-effectiveness would remain an important one in the future of independent living services. There is a need to develop new evaluation measures that are sensitive to both consumer needs and policy goals. Groups were reluctant to recommend any one set of evaluation criteria. One group recommended that the new National Institute of Handicapped Research make the issue of independent living evaluation one of its priorities in the months ahead.

The matter of evaluation not only applies to specific services but also to independent living centers as organizations which may be effective or ineffective. Participants suggested that each grant proposal submitted by an independent living center also inclue an evaluation plan. Reactions were mixed when discussing how much money should be set aside for evaluation. Some suggest 1.0 percent; others suggested no money.

Nearly all the groups recommended that consumers be involved in the evaluation process--in developing the evaluation plan, in constructing evaluation measures, and in analyzing the results. Some recognizing the need for objectivity, suggested that peer reviewers, independent researchers, state agencies, or consumer panels from other states also be used to evaluate an independent living center and its services.

A Backseat Topic

It is fair to say that the matters of fiscal accountability and evaluation were looked upon as necessary evils. They were viewed as things that compete with service delivery in terms of time and money. There is no doubt that this workshop topic took a backseat to the others in terms of participant interest.

Major Conferences Themes

Conference participants were not of one mind on all issues. In a few instances different mendations/suggestions were made with respect to a given issue. Nonetheless, we can discern a number of common themes emerging from the recommendations. While there may have been differences of opinion about specifices, there was a general consensus regarding the thrust of what the new regulations should be like. In addition, we can identify some assumptions that were shared by the various participants.

Need for Flexibility

Flexibility was one of the conference's major themes. Conference participants wanted flexibility in the areas of eligibility, state plan, grants to independent living centers, and the evaluation of independent living programs. Independent living services are still very new. Participants did not want to see the regulations impose any single model of service delivery. Instead they wanted to see a variety of methods tried and tested in response to different state needs.

Consistent with this theme, conferees did not want to see a host of requirements built into the regulations that were out of proportion to the funding that would be available in the near future. There was a fear that limited funds could easily be absorbed in meeting regulatory requirements leaving little left over for direct services. A more extensive set of requirements would be more appropriate if substantial funds were made available to implement Title VII.

Distrust of Vocational Rehabilitation Service Model

A pervasive theme throughout the conference was a distrust in traditional vocational rehabilitation services. Many consumers have been independent living advocates, in part, because of their mixed experiences with the vocational rehabilitation system.[9] The vocational rehabilitation service model assumes that the disabled individual will achieve a level of vocational achievement beyond which vocational rehabilitation services are no longer needed.[9] This is in marked contrast to independent living services which may be required indefinitely.

[9] This observation is in direct contrast to the high levels of confidence in the vocational rehabilitation system expressed by the House and Senate committees in their respective reports.

[10] Post-employment services are an exception. These vocational rehabilitation services can be rendered for a limited period of time to enable a person to maintain employment.

Independent living services can help an individual achieve a better standard and quality of living but are also needed to help an individual maintain that standard. As one workshop leader expressed it:

> You don't become unblind or undeaf because someone has given you independent living services. And just because you become employable or employed doesn't mean that you don't need . . . interpreter, teletype, or reader services.

Consumer Involvement

While participants did not want to see rigid requirements imposed, they did want to see strong regulatory language insisting on consumer involvement in all phases of independent living service delivery--in the development of the state plan, in the review of grant proposals, in the policy development and management of vendor agencies, in the monitoring of services, and in the evaluation of service effectiveness. The matter of consumer participation arose in each of the workshops. The theme of consumer participation is consistent with the independent living movement's basic philosophy that disabled persons must obtain and retain control over their own lives.

Maintenance of Effort

Participants were intent that existing programs continue to maintain their efforts in independent living as much as possible. They wanted to see Title VII dollars stretched to serve as many people as possible and not allocate the money to a few very expensive projects. "Let's not put our money into housing projects. Let HUD do that."

In Closing

Participants were very much aware that with the implementation of Title VII, the movement for independent living was at a new threshold. Title VII is the culmination of efforts begun in 1959 to gain legislative authority for independent living services. The quest for public funding of independent living services has twice suffered presidential veto in earlier administrations.

The independent living movement's success can be attributed mainly to the persistent efforts of disabled persons to control their own future. While Title VII marks a milestone in the history of the independent living movement, it presents risks as well. The chief risk is that new funding could bureaucratize the independent living movement as it becomes increasingly involved in organizing and maintaining independent living services. Conferees were very much alert to this risk. Thus, conference participants continued to recommend regulations and provisions that would encourage innovation and creativity characteristic of movement services to date.

APPENDICES

APPENDIX A

Title VII as Excerpted from P.L. 95-602

"TITLE VII—COMPREHENSIVE SERVICES FOR INDEPENDENT LIVING

"PART A—COMPREHENSIVE SERVICES

"PURPOSE

"SEC. 701. The purpose of this title is to authorize grants (supplementary to grants for vocational rehabilitation services under title I) to assist States in providing comprehensive services for independent living designed to meet the current and future needs of individuals whose disabilities are so severe that they do not presently have the potential for employment but may benefit from vocational rehabilitation services which will enable them to live and function independently.

Grants.
29 USC 796.
29 USC 720.

"ELIGIBILITY

"SEC. 702. Services may be provided under this title to any individual whose ability to engage or continue in employment, or whose ability to function independently in his family or community, is so limited by the severity of his disability that vocational or comprehensive rehabilitation services appreciably more costly and of appreciably greater duration than those vocational or comprehensive rehabilitation services required for the rehabilitation of a handicapped

29 USC 796a.

individual are required to improve significantly either his ability to engage in employment or his ability to function independently in his family or community. Priority of services under this part shall be given to individuals not served by other provisions of this Act.

"Comprehensive services for independent living."

"(b) For purposes of this title, the term "comprehensive services for independent living" means any appropriate vocational rehabilitation service (as defined under title I of this Act) and any other service that will enhance the ability of a handicapped individual to live independently and function within his family and community and, if appropriate, secure and maintain appropriate employment. Such services may include any of the following: counseling services, including psychological, psychotherapeutic, and related services; housing incidental to the purpose of this section (including appropriate accommodations to and modifications of any space to serve handicapped individuals); appropriate job placement services; transportation; attendant care; physical rehabilitation; therapeutic treatment; needed prostheses and other appliances and devices; health maintenance; recreational activities; services for children of preschool age, including physical therapy, development of language and communication skills, and child development services; and appropriate preventive services to decrease the needs of individuals assisted under the program for similar services in the future.

29 USC 720.

"ALLOTMENTS

29 USC 796b.

"SEC. 703. (a) (1) From sums made available for each fiscal year for the purposes of allotments under this subpart, each State whose comprehensive services plan has been approved under section 705 shall be entitled to an allotment of an amount bearing the same ratio to such sums as the population of the State bears to the population of all States. Except as provided in paragraph (2), the allotment to any State under the preceding sentence shall be not less than $200,000 or one-third of 1 percent of the sums made available for the fiscal year for which the allotment is made, whichever is greater, and the allotment of any State under this section for any fiscal year which is less than $200,000 or one-third of 1 percent of such sums shall be increased to the greater of the two amounts.

"(2) For purposes of this subsection, Guam, American Samoa, the Virgin Islands, the Northern Mariana Islands, and the Trust Territory of the Pacific Islands shall not be considered as States and shall each be allotted not less than one-eighth of 1 percent of the amounts made available for purposes of this subpart for the fiscal year for which the allotment is made.

"(b) Amounts necessary to increase the allotments of States under paragraph (1) or to provide allotments under paragraph (2) shall be derived by proportionately reducing the allotments of the remaining States under paragraph (1), but with such adjustments as may be necessary to prevent the allotment of any such remaining States from being thereby reduced to less than the greater of $200,000 or one-third of 1 percent of the sums made available for purposes of this subpart for the fiscal year for which the allotment is made.

"(c) Whenever the Commissioner determines that any amount of an allotment to a State for any fiscal year will not be utilized by such State in carrying out the purposes of this title, he shall make such amount available for carrying out the purposes of this section to one or more of the States which he determines will be able to use additional amounts during such year for carrying out such purposes. Any amount

made available to a State for any fiscal year pursuant to the preceding sentence shall, for the purposes of this section, be regarded as an increase in the State's allotment (as determined under the preceding provisions of this section) for such year.

"PAYMENTS TO STATES FROM ALLOTMENTS

"SEC. 704. (a) From each State's allotment for a fiscal year under section 703, the State shall be paid the Federal share of the expenditures incurred during such year under its State plan approved under section 705. Such payments may be made (after necessary adjustments on account of previously made overpayments or underpayments) in advance or by way of reimbursement, and in such installments and on such conditions as the Commissioner may determine. 29 USC 796c.

"(b)(1) The Federal share with respect to any State for any fiscal year shall be 90 percent of the expenditures incurred by the State during such year under its State plan approved under section 705. Federal share.

"(2) The non-Federal share of the cost of any project assisted by an allotment under this subpart may be provided in kind.

"(3) For the purpose of determining the Federal share with respect to any State, expenditures by a political subdivision of such State shall, subject to regulations prescribed by the Commissioner, be regarded as expenditures by such State.

"STATE PLANS

"SEC. 705. (a) In order to be eligible for grants under this part, a State shall submit to the Commissioner a State plan for a three-year period for providing comprehensive services for independent living to severely handicapped individuals, and, upon request of the Commissioner, shall make such annual revisions in the plan as may be necessary. Each such plan shall— Submittal to Commissioner. 29 USC 796d.

"(1) designate the designated State unit of such State as the agency to administer the programs funded under this part;

"(2) demonstrate that the State has studied and considered a wide variety of methods for providing comprehensive services to severely handicapped individuals (such as regional and community centers, halfway houses, and patient-release programs) and that the State will provide, to the maximum extent feasible, meaningful alternatives to institutionalization;

"(3)(A) describe the quality, scope, and extent of the comprehensive services for independent living to be provided to handicapped individuals under this part, and specify the State's goals and plans with respect to the distribution of funds received under part B of this title; and

"(B) provide satisfactory assurances that facilities used in connection with the delivery of services assisted under this part and part B of this title will comply with the Act of August 12, 1968, commonly known as the Architectural Barriers Act of 1968; 42 USC 4151 note.

"(4) provide assurances that (A) an individualized written rehabilitation program meeting the requirements of section 102 will be developed for each handicapped individual eligible for independent living services under this part; (B) such services will be provided in accordance with such program; and (C) that such program be coordinated with the individualized written rehabilitation program, habilitation plan, or education program for such individual required under section 102 of this Act, section 112 of the Developmental Disabilities Services and Facilties Con- 29 USC 722. 42 USC 6011.

20 USC 1412, 1413.

struction Act, and sections 612(4) and 614(a)(5) of the Education for All Handicapped Children Act of 1975, respectively;

"(5) provide assurances that the State will conduct periodic reviews of the progress of individuals assisted under this title to determine whether services provided to such individuals should be continued, modified, or discontinued;

"(6) provide assurances that special efforts will be undertaken to provide technical assistance to urban and rural poverty areas with respect to the provision of comprehensive services for severely handicapped individuals and describe such efforts;

"(7) provide assurances that handicapped individuals shall have a substantial role in developing the State plan;

"(8) provide assurances that not less than 20 percent of the funds received by a State under this part shall be used to make grants to local public agencies and private nonprofit organizations for the conduct of independent living services except that the Commissioner may waive the requirement of this clause if the Commissioner determines, on the basis of evidence submitted by the State, that such State cannot feasibly use the funds required to be expended under this section for the purposes of this clause; and

"(9) contain such other information, and be submitted in such form and in accordance with such procedures, as the Commissioner may require.

Approval.

"(b) As soon as practicable after receiving a State plan submitted under subsection (a), the Commissioner shall approve or disapprove such plan. The Commissioner shall approve any State plan which he determines meets the requirements and purposes of this section. The provisions of subsections (b), (c), and (d) of section 101 of this Act shall apply to any State plan submitted to the Commissioner pursuant to this section, except that for purposes of this section, all references in such subsections to the Secretary shall be deemed to be references to the Commissioner.

29 USC 721, *Ante*, pp. 2958, 2959.

"PART B—CENTERS FOR INDEPENDENT LIVING

"GRANT PROGRAM ESTABLISHED

29 USC 796e.

"SEC. 711. (a) The Commissioner may make grants to any designated State unit which administers the State plan under section 705 to provide for the establishment and operation of independent living centers, which shall be facilities offering the services described in subsection (c)(2).

Application.

"(b) No grant may be made under this section unless an application therefore has been submitted to and approved by the Commissioner. The Commissioner may not approve an application for a grant unless the application—

"(1) contains assurances that the designated State unit will use funds provided by such grant in accordance with subsection (c); and

"(2) contains such other information, and is submitted in such form and in accordance with such procedures, as the Commissioner may require.

"(c) An application by a public or nonprofit agency or organization for such grant shall—

"(1) provide assurances that handicapped individuals will be substantially involved in policy direction and management of such center, and will be employed by such center;

"(2) contain assurances that the independent living center to be assisted by such grant shall offer handicapped individuals a combination of independent living services, including as appropriate— Independent living services.

"(A) intake counseling to determine the client's need for specific rehabilitation services;

"(B) referral and counseling services with respect to attendant care;

"(C) counseling and advocacy services with respect to legal and economic rights and benefits;

"(D) independent living skills, counseling, and training, including such programs as training in the maintenance of necessary equipment and in jobseeking skills, counseling on therapy needs and programs, and special programs for the blind and deaf;

"(E) housing and transportation referral and assistance;

"(F) surveys, directories, and other activities to identify appropriate housing and accessible transportation, and other support services;

"(G) health maintenance programs;

"(H) peer counseling;

"(I) community group living arrangements;

"(J) education and training necessary for living in the community and participating in community activities;

"(K) individual and group social and recreational activities;

"(L) other programs designed to provide resources, training, counseling, services, or other assistance of substantial benefit in promoting the independence, productivity, and quality of life of handicapped individuals;

"(M) attendant care and training of personnel to provide such care; and

"(N) such other services as may be necessary and not inconsistent with the provisions of this title; and

"(3) contain such other information, and be submitted in such form and in accordance with such procedures, as the Commissioner may require.

"(d) If, within six months after the date in each fiscal year on which the Commissioner begins to accept applications from designated State units under this section, a designated State unit in a State has not submitted such an application, the Commissioner may accept applications for grants under this section from local public agencies or private nonprofit organizations within such State. After the receipt of such applications, the Commissioner may make grants to such agencies or organizations for the purpose of establishing independent living centers to provide the services described in subsection (c)(2).

"PART C—INDEPENDENT LIVING SERVICES FOR OLDER BLIND INDIVIDUALS

"SERVICE PROGRAM ESTABLISHED

"SEC. 721. (a) The Commissioner may make grants to any designated State unit to provide independent living services to older blind individuals. Such services shall be designed to assist an older blind individual to adjust to his blindness by becoming more able to care for his individual needs. Such services may include— Grants. 29 USC 796f.

"(1) services to help correct blindness such as (A) outreach services, (B) visual screening, (C) surgical or therapeutic treatment to prevent, correct, or modify disabling eye conditions, and (D) hospitalization related to such services;

"(2) the provision of eyeglasses and other visual aids;

"(3) the provision of services and equipment to assist an older blind individual to become more mobile and more able to care for himself;

"(4) mobility training, Braille instruction, and other services and equipment to help an older blind individual adjust to blindness;

"(5) guide services, reader services, and transportation; and

"(6) any other appropriate services designed to assist a blind person in coping with daily living activities, including supportive services or rehabilitation teaching services.

Application.

"(b) No grant may be made under this section unless an application therefor, containing such information as the Commissioner may require, has been submitted to and approved by the Commissioner. The Commissioner may not approve any application for a grant unless the application contains assurances that the designated State unit will seek to incorporate any new methods and approaches relating to the services described in subsection (a) into its State plan for independent living services under section 705 of this title.

Funds.

"(c) Funds received under this section by any designated State unit may be used to make grants to public or private nonprofit agencies or organizations to—

"(1) conduct activities which will improve or expand services for older blind individuals and help improve public understanding of the problems of such individuals; and

"(2) provide independent living services to older blind individuals in accordance with the provisions of subsection (a).

"Older blind individual."

"(d) For purposes of this section, the term 'older blind individual' means an individual aged fifty-five or older whose severe visual impairment makes gainful employment extremely difficult to attain but for whom independent living goals are feasible.

"PART D—GENERAL PROVISIONS

"PROTECTION AND ADVOCACY OF INDIVIDUAL RIGHTS

Grants.
29 USC 796g.

"SEC. 731. (a) The Commissioner may make grants to States to establish systems to protect and advocate the rights of severely handicapped individuals. In order to be eligible for a grant under this section, a State shall provide the Commissioner with assurances that any system established with grants made under this section shall have the authority to pursue legal, administrative, and other appropriate remedies to insure the protection of the rights of such individuals receiving services under this title within the State. A State must provide that such system will be independent of any designated State unit that provides services under this part to such individuals.

Application.

"(b) No grant may be made under this section unless an application therefor has been submitted to the Commissioner containing such information and in such form and in accordance with such procedures as the Commissioner may, by regulation, prescribe.

"EMPLOYMENT OF HANDICAPPED INDIVIDUALS

Affirmative action.
29 USC 796h.

"SEC. 732. As a condition of providing assistance under this title, the Secretary shall require that each recipient of assistance take

affirmative action to employ and advance in employment qualified handicapped individuals on the same terms and conditions required with respect to the employment of such individuals under the provisions of this Act which govern employment (1) by State rehabilitation agencies and rehabilitation facilities, and (2) under Federal contracts and subcontracts.

"PART E—AUTHORIZATIONS

"AUTHORIZATION OF APPROPRIATIONS

"SEC. 731. (a) For the purpose of carrying out the provisions of parts A, B, and C of this title, there are authorized to be appropriated $80,000,000 for the fiscal year ending September 30, 1979, $150,000,000 for the fiscal year ending September 30, 1980, $200,000,000 for the fiscal year ending September 30, 1981, and such sums as may be necessary for the fiscal year ending September 30, 1982. 29 USC 796i.

"(b) From the amounts authorized to be appropriated under this section, an amount shall be made available for the purpose of carrying out the provisions of Part C of this title in an amount not in excess of 10 percent of the amount made available for carrying out the provisions of subpart 1 of Part A of this title.

"(c)(1) For the purpose of carrying out Part D of this title, there are authorized to be appropriated such sums as may be necessary for the fiscal year ending September 30, 1979, and for each of the three succeeding fiscal years, but in no event shall such sums exceed $6,000,000 for the fiscal year ending September 30, 1979, $7,500,000 for the fiscal year ending September 30, 1980, and $9,000,000 for the fiscal year ending September 30, 1981.

"(2) The provisions of section 1913 of title 18 of the United States Code shall be applicable to all moneys authorized under the provisions of this subsection."

CONFORMING AMENDMENT

SEC. 302. The table of contents for the Rehabilitation Act of 1973, as amended in section 120(c)(6) and section 202(b), is further amended by adding at the end thereof the following:

"TITLE VII—COMPREHENSIVE SERVICES FOR INDEPENDENT LIVING

"PART A—COMPREHENSIVE SERVICES

"Sec. 701. Purpose.
"Sec. 702. Eligibility.
"Sec. 703. Allotments.
"Sec. 704. Payments to States from allotments.
"Sec. 705. State plans.

"PART B—INDEPENDENT LIVING CENTERS

"Sec. 711. Grant program established.

"PART C—INDEPENDENT LIVING SERVICES FOR OLDER BLIND INDIVIDUALS

"Sec. 721. Service program established.

"PART D—GENERAL PROVISIONS

"Sec. 731. Protection and advocacy of individual rights.
"Sec. 732. Employment of handicapped individuals.

"PART E—AUTHORIZATIONS

"Sec. 731. Authorization of appropriations.".

APPENDIX B

Workshop Discussion Questions

Workshop I: Issues Relating to Eligibility

1. In the face of limited appropriations, should the regulations spell out which groups should receive priority for Part A services? The Act states that: "Priority of services under this part shall be given to individuals not served by other provisions of the Act (Sec. 702(a))."
2. Since Title VII specifies no upper or lower age limit for services (would include pre-school children), should/can regulations narrow the age range especially during the early years of funding?
3. How comprehensive an eligibility determination should be required?
4. The Act implies that services are to be rendered to those who have the potential "to improve significantly either his ability to engage in employment or his ability to function independently in his family or community" (Sec. 702 (a)). How is potential to be determined? How specific is this determination to be? Is there an implied termination of services whenever there is no "significant improvement?" Is it implied that there is a need for some services to be provided indefinitely to assure "enhanced ability?"
5. Who is to determine eligibility? The state vocational rehabilitation agency? The service provider?
6. Should any of the listed Title VII services be means tested? Which ones, if any?
7. Should there be separate determinations of eligibility for Title I and Title VII services?

Workshop II: Maintenance of Effort

A. Maintaining Effort under Title I and Relationship of Title VII to Ongoing State Vocational Rehabilitation Programs.

1. Title VII does not address paying administrative costs for programs developed under Title VII. Can it be assumed that these costs are inherent to Title VII or must/could the states pick up these costs under their Title I allotment? (Remember: Part A speaks of grants **supplemental** to those of Title I.) By burying administrative costs under Title I, more funds would be left for direct services under Title VII.
2. How should services rendered under Title VII interface/dovetail with services rendered through innovation and expansion (I&E) projects?
3. When is a service an independent living service and when is it an extended evaluation service?
4. How can individual eligibility be shifted between Title I and Title VII without disruption or administrative difficulty?
5. Should vocational rehabilitation counselors carry separate or joint caseloads? Should individuals receiving independent living services be considered "a case" in the traditional vocational rehabilitation sense of the term?
6. Should there be similar reporting requirements for Title I and Title VII services? Should R-300s or other forms be used?
7. To what extent should individuals be evaluated to determine need for services? Should the evaluation be as extensive as that required for Title I services?
8. Of the vocational rehabilitation services listed in section 103 of Title I, which are appropriate for inclusion in the enumeration of services envisioned in Sec. 702? If these services are provided, would they be paid from Title I funds? If so, would this require a separate determination of eligibility for Title I?
9. How can services now funded through Title I be kept from being refinanced under Title VII?

B. Maintaining Effort under Various Non-Vocational Rehabilitation Programs.

10. What is meant by coordination with section 112 of the DD Act and sections 614(4) and 614(5) of the Education for all Handicapped Children Act of 1975 (Sec. 705(a) (4))? Is there a danger that services rendered under these authorities may be refinanced, in part, under Title VII?
11. Can/should regulations be worded to require states to deny attendant care to those who are eligible for attendant care under Medicaid or Title XX.
12. Should the designated state unit be required to enter into interagency agreements with state public welfare agencies to have attendant care financed under Medicaid or Title XX?
13. How can the following services be maintained under their present authorities: housing, architectural modifications, transportation, provision of prostheses and special devices, health maintenance, physical therapy, communication skills, etc.?
14. Should Title VII be a residual service program or become a first-line service program?

Workshop II: State Plan

1. Should the regulations specify what kind of studies should precede the formulation of a state plan (Sec. 705(a) (2))? Should Title VII monies be available for such studies?
2. In developing "meaningful alternatives to institutionalization" (Sec. 705(a) (2)), should the states, for example, be required to undertake efforts to identify those now in institutions who could benefit from independent living services?
3. Should the regulations require that the state plan spell out the activities of, and arrangements with, other state agencies in meeting the independent living goals of the state's disabled citizens?
4. What constitutes "technical assistance to urban and rural poverty areas" (Sec. 705(a) (6))?
5. Should the regulations spell out the criteria making other public agencies and nonprofit organizations eligible for Title VII grants?
6. What should be the effective dates of the Title VII state plans? Coincidental with the fiscal year?
7. Should regulations specify what will be required in the annual updates of the Part A state plan? What should be included in these annual reports?
8. Should regulations spell out the evidence the states must submit in order to justify a request for a waiver of the 20-percent set-aside as required in (Sec. 705(a) (8))?
9. How many, or which services listed in Sec. 702(b) should be provided in order for a state plan to be approved? Should a certain minimum list of services be required for a state plan to be approved?
10. How and to what extent should consumers be involved in the development of state plans (Sec. 705)?
11. Sec. 705(a) (4) calls for an IWRP that meets the requirements of Sec. 102. Should there be any additional requirements imposed to insure greater consumer participation?

Workshop IV: Centers For Independent Living

1. Since the "designated state unit" administering the state plan under Part A is to be the principal grantee under Part B, to what extent should the centers for independent living be made beholden to the state vocational rehabilitation agencies? What regulatory language can be drafted to avoid making centers for independent living mere extensions of the state's vocational rehabilitation programs?

2. Can a consumer group apply for funds under Part B independently of the state agency (aside from Sec. 711 (d))?
3. Since Part B grants are to be made to the unit which administers the Part A formula program (except as provided in(Sec.711 (d)), must an approved state plan be in place before a state can obtain Part B funds?
4. Does Part B permit planning grants to be issued to consumer groups in order to help them obtain the technical assistance necessary to develop good applications?
5. Does the absence of an approved state plan in itself satisfy the requirements of section 711 (d), that is, automatically satisfy the 6-month wait before a local organization (e.g., center for independent living) becomes an eligible grantee for a Part B grant?
6. Can a state announce its intention **not** to participate in Part B in any year so that RSA can move immediately to entertaining applications from nonprofit and public agencies in that state, rather than wait 6 months?
7. What should be the relationship between independent living centers and comprehensive rehabilitation centers authorized under section 305 of the Act?
8. Can an independent living center also be a comprehensive rehabilitation center and receive funds under both Title III (Sec. 305) and VII?
9. Sec. 711 (c) (1) provides that "handicapped individuals...be substantially involved in policy direction and management of such center, and...be employed by such center..." How should substantially involved be defined? Should grants only be made to centers who have at least 50 or 66.7 percent consumer representation on their boards of directors? Who are consumers? What about the role of parents of developmentally disabled children?
10. Should states be allowed discretion in setting minimum standards as to what constitutes substantial involvement under Sec. 711(c) (1)?

Workshop V: Funding & Accountability

1. How are the amounts appropriated under Sec. 731(a) to be allocated among Parts A, B, and C? Note also Sec. 731(b) limiting expenditures under Part C.
2. How should the minimum 20-percent set aside under Part A (Sec. 705)(a) (8)) for local organizations (e.g., independent living centers) be disbursed?
3. To what extent should the funding and delivery of Part A services or other services be modeled after traditional Title I vocational rehabilitation services?
4. What should be allowable funding for staffing start-up time and other types of overhead costs?
5. Should state agencies purchase services from vendor agencies through the use of grants? Contracts? Fee-for-service?
6. What fiscal controls should be specified in the regulations?
7. What Part A services should be provided directly by the state agency? Which services ought to be rendered by a vendor agency or organization?
8. Must expenditures under Parts A & B be identified with or traceable to a specific individual?
9. How should the progress of individuals receiving Title VII services be evaluated (Sec. 705(a) (5))?
10. How is the effectiveness of independent living centers to be determined? Who should evaluate independent living centers and services? Should funding be set aside for evaluation of independent living services?

APPENDIX C

Workshop Leaders	RSA Recorders
Workshop I: Eligibility	
Mary Akerley Debbie Kaplan	Richard Melia Ann Queen Charles Smolkin
Workshop II: Maintenance of Effort	
Craig Mc Garvey Bob McHugh	Rose Ann Rafferty Peter McCabe
Workshop III: State Plan	
Dave Haley Janet Minch	Robert Jones Arthur Cox
Workshop IV: Centers for Independent Living	
Brenda Premo Susie Dahl	Edyth Glazer Roberta Church
Workshop V: Funding/Accountability	
Tamara Bibb Max Starkloff	Allen Menefee Cynthia Sandvig

APPENDIX D

Conference Participants

Mary Akerley
Ingo Antonisch
John Bell
Dave Berglund
Tamara Bibb
Barbara Brasel
Charles Carr
Mel Carter
John Collins
Bruce Curtis
Susie Dahl
Cynthia Davis
Judy Dennis
Ethan Ellis
Nancy Erickson
Paula Ewers
Marc Fiedler
Pat Figueroa
Mervin Flander
Fred Francis
Lex Frieden
Helen Goodkin
David Haley
Kathy Harmon
Marguerite Harmon
Judy Heumann
Bob Hutton
Robin Jackson
Harriet Johnson
Lin Johnson
Debbie Kaplan
John Kemp
Warren King
Randy Kitch
Cynthia Kolb
Barbara Lee
Joan Leon
Eric Lucero
Craig Mc Garvey
Bob McHugh
Marjorie Moore
Mary Noble
Chris Opdahl
Eugene Petersen
Lawrence Peterson
Pat Pound
Brenda Premo
Marilyn Rea
Edward Roberts
Virginia Roberts
Greg Sanders
Robert Sanderson
Dick Santos
Marilyn Saviola
Thelma Schones
Lois Schwab
Jack Schmitt
Peter Smith
Max Starkloff
Cordelia Toles
Sharon Van Meter
Ann Waltz
Teg Wenker
Ralph White
Elaine Wilcox
Eleanor Wilt
William Woodrick
Ray Zanella
Irving Zola

Other Attendees

Keith Beichner
Frank Bowe
James Burr
John Chappell
Roberta Church
Charlotte Coffield
Robert Counts
Arthur Cox
Patria Forsythe
Joni Fritz
Gail Gibran
Bob Hale-Harborro
Harry Hall
Richard Hill
Robert Humphreys
Richard Johnson
Robert Jones
John Lavan
Laura Levine
Peter McCabe
Ranjit Majumder
Evelyn Provitt
Ann Queen
Rose Ann Rafferty
James Ramseur
Carol Rievers
Helga Roth
Jeanne Rubin
Frederick Sachs
Cynthia Sandvig
Harold Shay
Mary Smith
Charles Smolkin
Miriam Stubbs
Claude Whitehead
Susan Zylstra

APPENDIX E

Conference Staff

RSA Staff

Delorise Anderson
William Bean
Elizabeth Goins
Richard Leclair
Dolores Meler
Richard Melia
Allen Menefee
Christine Tansey
Louise Vaughan
Boyce Williams
Robert Winn

Tufts Staff

Susan Dailey
Gerben DeJong
Fred Fay
Barry Goldsmith
Ruth House
Janet Minch

About the Independent Living Studies Program

The Independent Living Studies Program is one of the core areas of research, evaluation, and training at the Tufts RT-7 Center. It serves as a regional and national resource on independent living issues such as income assistance, attendant care, health care policy, economic disincentives, disability determination, evaluation of disability outcomes, and federal legislation. Since its inception in 1978, the program's research and evaluation effort has attempted to develop an interdisciplinary approach to independent living issues and policy. It draws heavily on the perspectives of medicine, the social sciences, evaluation research, and rehabilitation.

In addition to its research program, the staff is often asked to provide technical assistance to private organizations and to governmental agencies at the federal and state level. These consultation services are only available outside the formal RT−7 program.

The staff has been closely associated with the movement for independent living in New England. Members of the staff have been instrumental in the early development of the Boston Center for Independent Living (BCIL) and in the development of attendant care services. Members of the staff presently serve on the Interagency Council for Independent Living (ICIL) and have been active in promoting appropriate housing for disabled persons in the local area.

The following publications and reports on independent living have been prepared by members of the staff for public dissemination:

	Price
Fay, Frederick A. 1976 "Independent Living for Individuals with 'Severe Disabilities': The Federal Outlook." Boston: Tufts-New England Medical Center.	____
Corcoran, Paul, Frederick A. Fay, et. al. 1977 **The BCIL Report**, Peter Reich, ed. Boston: Tufts-New England Medical Center.	____
DeJong, Gerben 1977 **The Need for Personal Care Services by Severely Physically Disabled Citizens of Massachusetts.** Personal Care & Disability Study, Report No. 1. Waltham, Massachusetts: Brandeis University, Levinson Policy Institute.	$2.00
DeJong, Gerben 1977 **Meeting the Personal Care Needs of Severely Physically Disabled Citizens of Massachusetts.** Personal Care & Disability Study, Report No. 2. Waltham, Massachusetts: Brandeis University, Levinson Policy Institute.	$4.00
DeJong, Gerben 1978 "Disability, Home Care, and Relative Responsibility: A legal Perspective." A paper presented to the American Congress of Rehabilitation Medicine, New Orleans, November 16, Boston: Tufts-New England Medical Center.	$1.00
DeJong, Gerben 1978 "The Movement for Independent Living: Origins, Ideology and Implications for Research." A paper presented to the American Congress of Rehabilitation Medicine, New Orleans, November 17. Boston: Tufts-New England Medical Center. Subsequently published by the University Center for International Rehabilitation, Michigan State University, East Lansing, Michigan.	$2.00
DeJong, Gerben 1979 **Report of the National Conference on Independent Living Service Regulations**. Boston: Tufts-New England Medical Center.	$1.00
DeJong, Gerben 1979 "Independent Living: From Social Movement to Analytic Paradigm." **Archives of Physical Medicine and Rehabilitation** (forthcoming).	____

DeJong, Gerben and Teg Wenker
1979 "Attendant Care as a Prototype Independent Living Service." **Archives of Physical Medicine and Rehabilitation** (forthcoming).

Only the items that are priced are currently available. All supplies are very limited. Listed prices help to cover reprinting costs when supplies are exhausted. Those requesting publications should sent their remittance to:

Ms. Susan Dailey
Box 190
New England Medical Center Hospital
171 Harrison Ave.
Boston, Mass. 02111

Checks should be made payable to New England Medical Center Hospital.