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OA/ID Number: 52075
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Folder Title:
IL [Independent Living] Leadership Meeting '82

Stack:

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Section:

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Position:

Monday, July 26

9:00
Rolls & Coffee

9:30
INTRODUCTION/OVERVIEW OF PLANNING
SESSION
Lisa Walker, IEL
Barry Bernstein, VCIL

10:00
HOW INDEPENDENT LIVING PROGRAMS
DEVELOP
Moderator, Chris Palames

10:00 - 11:00
Organizational History:
Paraquad, Inc., Max Starkloff

11:00 - 12:00
Organizational History:
Vermont Center for Independent
Living and Stavros Foundation
Barry Bernstein & Chris Palames

12:00 - 1:30
LUNCH BREAK

1:30 - 2:30
Organizational History:
Access Living of Metropolitan Chicago
Marca Bristo

2:30 - 3:30
Organizational History:
Community Services Center for the
Disabled
Ray Zanella

4:00 - 5:00
SMALL GROUP SESSIONS led by
presentors

- Did the morning and afternoon presentations reflect your organization's developmental experience?
- Can you pinpoint the internal or external factors that have had a major effect on your program's development?

6:00 - 7:30
DINNER at Kellogg Center:
Red Cedar A

8:00 - 9:30
RECONVENE: Review small group
discussions - Michael Moore

Briefing on Tuesday morning's
session - Chris Palames

Tuesday, July 27

9:30
Rolls & Coffee

10:00
MOVEMENT OVERVIEW
Group Discussion led by Ed Roberts
- Independent Living: dynamics of
integrating a program of service
delivery with social action
- Independent living in relation to
the Disability Rights Movement as a
whole
- What tensions emerge as we struggle
with survival trying to work on
movement advocacy today?
- What is the potential for resolving
this tension in today's economy?
- How do you keep your integrity
in the process?
- In this light, what will be the
impact of the current crises on ILPs?

12:00 - 1:30
LUNCH at Kellogg Center:
Red Cedar A

1:30 - 5:00 (Self-Initiated/Optional)
ORGANIZATIONAL/OPERATIONAL/CLINICS
- Specific issues but looked at on
a broad focus
- Will have newsprint with sessions
mentioned to date. People will be
able to add session titles during
the conference for consideration

TIME ALSO AVAILABLE FOR OTHER
ACTIVITIES

5:30 - DINNER BREAK

7:30 - 9:30
SETTING A CONTEXT FOR ACTION
- Long range objectives of the
disability rights movement

Lex Frieden: short presentation of
different possibilities: taking into
consideration different legal and
political changes. Looking at the
whole picture (transfer of payments,
transportation, housing).

Michael Moore: group discussion
- Can we clearly articulate what we
want for the future? Where do we
want to be as a movement as
distinguished from the defenders of
programs?

Wednesday, July 28

9:30
Rolls & Coffee

10:00
STRATEGIES FOR ILPs IN THE 1980s
Group Discussion led by Pat Figueroa,
Barbara Bradford, Charles Carr

12:00 - 1:30
LUNCH at Kellogg Center:
Red Cedar A

1:30 - 5:00 (Self-Initiated/Optional)
ORGANIZATIONAL/OPERATIONAL/CLINICS
Reception sponsored by the Michigan
ILPs at the Kellogg Center

7:30
DINNER at Kellogg Center:
Red Cedar A

AGENDA NOTES: 1) The philosophy, structure and operations of each ILP can really be understood only in light of its individual history. Each responds continually to local environmental influences which affect its development in complex ways. By looking at how programs evolve over time we should be able to better understand the forces which influence development and at the same time gain perspective at the outset of the conference on the range of viewpoints and experiences presented. Four presentations will be made on ILPs, each representing different structures and styles of operation. Following these, the conference will break into small groups to analyze the presentations and compare them with the experiences of all the other programs represented. From these discussions patterns may emerge which indicate developmental dynamics common to many or all ILPs.

2) Most ILPs perceive themselves to be fundamentally different from traditional social service agencies, but what in fact are the differences? One key clearly is the quality of the relationship between the programs and their constituency. Disabled people not only play vital roles in the programs, the programs as a whole are often seen as direct expressions of the disabled community's struggle for self-determination. While specific language may vary, most ILPs will describe themselves as having two principle functions: service delivery and advocacy. We hope that through an analysis of the way these two dimensions are integrated in practice, we will better understand what the conference participants feel to be the creative, valuable, and effective aspects of their programs. The Disability Rights Movement is threatened today by an economic recession and the ascendancy of conservative politics with attendant developments in federal and state social policies. We will explore the nature of these crises and possible responses to them. These will be considered with attention to independent living's relationship to and role within the Disability Rights Movement.

3) Through discussion of organizational histories, we will hopefully gain insight on patterns of development shared by ILPs. In addition to gaining this perspective on programs, we want to focus on particular organizational or operational problems that ILPs have encountered or are currently experiencing. We thought a good forum to explore the issues, identify their causes, and generate solutions would be afternoon clinics. As it is envisioned, each clinic will focus on a single issue. People will be able to select the clinic that interests them most. Leadership of workshops will come from the pool of participants and participation in these sessions is optional, thereby assuring serious workshops.

4) Long range goals. The Independent Living Movement has not yet formulated its long range goals. Lacking such a clear sense of direction, our effectiveness is sharply curtailed, and we are more often than necessary forced to react to rather than initiate significant developments. Assuming greater initiative is particularly important during a period of rapid change in national social policy, we will discuss the potential for supporting on-going analyses and planning of long range policies and programmatic goals for independent living.

Thursday, July 29

9:30
Rolls & Coffee

10:00
FUNCTIONS OF NETWORK
Barry Bernstein & Judy Heumann

12:00 - 1:30
LUNCH BREAK

1:30 - 5:00
PROGRAM FOR LEADERSHIP NETWORK
Max Starkloff
- What are the priority questions we
need to address or get addressed?
- What would it take to accomplish
your vision of where things should
be in ten years?
- what is practical?
- what is feasible?
- where do we start?
- What resources are available?
- List specific action steps,
implications
- Prioritize options

6:00
DINNER at Kellogg Center:
Red Cedar A

Friday, July 30

9:00
Rolls & Coffee

9:30
SOLIDIFY PLAN OF ACTION
Chris Palames
Michael Moore
- Nail down next strategies
- Summary and conclusion

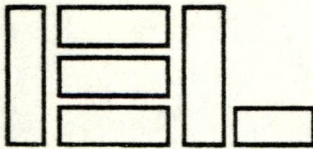
12:00
DEPART

THE INDEPENDENT LIVING
LEADERSHIP STRATEGIES PROJECT

AGENDA

Trill

Importation



THE INSTITUTE FOR EDUCATIONAL LEADERSHIP, INC.

THE INDEPENDENT LIVING LEADERSHIP STRATEGIES PROJECT
KELLOGG CENTER FOR CONTINUING EDUCATION
JULY 25 - JULY 30, 1982

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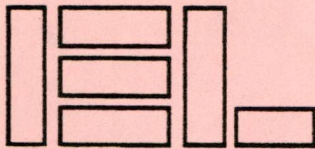
CONFERENCE RECORDER

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PROJECT STAFF

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THE INSTITUTE FOR EDUCATIONAL LEADERSHIP, INC.

The Independent Living Leadership Strategies Project ORGANIZATIONAL HISTORY

Small Groups

LEADERS: (1) Barry/Chris

Pat Figueroa
Theresa Preda
Ed Roberts

(2) Marca Bristo

Lynnae Rutledge
Charlie Carr
Geni Laurie
Michael Winters

LEADERS: (3) Ray Zanella

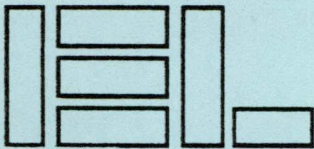
Barbara Bradford
Lex Frieden
Tony Serra
John Ross

(4) Max Starkloff

Bernie Cantu
Judy Heumann
Bob Funk
Jean Mankowsky

QUESTIONS:

- How was the presenter recruited to the ILP?
- What was the external environment of the organization? (geographic size, social, political circumstances)
- Structure of the program?
- Prehistory of the organization? What was being provided before and by whom? How did the program get started? (critical factors)
- How strong was the struggle away from other, non consumer based organizations?
- Funding -- its impact on program services, structure.
- Internal Resource Dynamics
 - skills mastered
 - staff recruitment, development and training
 - authority, power structures
 - service delivery strategies -- how effective are they? Have they changed over time? What impacted them most?



THE INSTITUTE FOR EDUCATIONAL LEADERSHIP, INC.

THE INDEPENDENT LIVING LEADERSHIP STRATEGIES PROJECT
Kellogg Center for Continuing Education
July 25 - July 30, 1982

EVALUATION SURVEY

1. How valuable do you feel this seminar
was for you?

1	2	3	4	5
little				very

2. What was the most valuable in this seminar
for you?

3. What had least value for you?

4. General comments and suggestions.

DREDF

**Disability Rights Education
and Defense Fund, Inc.**

LAW,
PUBLIC POLICY,
TRAINING AND
TECHNICAL
ASSISTANCE

July 15, 1982

2032 San Pablo Avenue
Berkeley, California 94702

(415) 644-2555
(TDD) 644-2629

Dear Friends,

Enclosed please find the following "UPDATE" information:

- A letter outlining events pertaining to revision of Section 504; the present status of PL 94-142; and information on the Rowley decision;
- A sample letter to be used by you requesting field hearings and an extended comment period should the Department of Justice publish proposed changes in the §504 coordination guidelines;
- A brief review of proposed revisions in PL 94-142;
- A copy of a resolution adopted by the President's Committee on Mental Retardation supporting no changes in PL 94-142 and Section 504;
- Summaries of the Rowley decision by the National Center for Law and the Deaf and by DREDF;
- An article published in the Washington Post (6/29/82) on the Rowley decision

In order to help us defray costs, please copy and distribute this information throughout your network.

Sincerely,



Robert J. Funk
Executive Director/Attorney



Mary Lou Breslin
Deputy Director

DREDF

**Disability Rights Education
and Defense Fund, Inc.**

LAW,
PUBLIC POLICY,
TRAINING AND
TECHNICAL
ASSISTANCE

July 7, 1982

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*** ALERT ***

CALL FOR NATIONAL ACTIVITY

To: 504 Contacts in All 50 States

Re: Updates on Section 504, Public Law 94-142

Friends:

We are reaching a point where publication of regulations for Public Law 94-142 (the Education of All Handicapped Children Act) and Section 504 is imminent. For those of you who have been following this issue closely, you know that the Administration's proposals have improved somewhat from bad to better directly as a result of the thousands of letters you have sent in to the White House, the Department of Justice and the Department of Education. However, as we move closer to the date of publication, it is vital that we be assured by the Administration that the public comment period will allow sufficient time for us to respond and that regional hearings be held to allow you to express your opinions on these changes. These assurances must be received now.

The Present Status of 504

- Fact: No later than July 16th., the final Department of Justice draft of the proposed 504 Guidelines will be sent to the Office of Management and Budget.
- Issue: OMB has the authority under Executive Order 12291 to hold the guidelines for review and revision for up to 60 days (this could mean a week and could mean up to a full two months).
- Fact: As a direct result of your letters, the Department of Justice drafts have improved somewhat over the last few months.
- Issue: OMB has not been directly involved in writing portions of the 504 drafts since early

An organization
dedicated to the Independent
Living Movement and
the Civil Rights of Persons
with Disabilities

Dear

I am strongly opposed to any changes in the 1978 §504 Inter-agency Coordination Guidelines which are currently under review by the U.S. Department of Justice.

Despite the fact that disabled people, their parents, advocates and supporters throughout the U.S. have raised their voices to protest any changes in the existing guidelines, we understand that the Department of Justice is moving ahead with plans to publish proposed changes in the Federal Register for public comment.

When and if the Department of Justice publishes proposed changes, it is imperative that the disabled community be afforded an adequate amount of time to prepare responses to any detrimental changes and have an opportunity to provide expert testimony on the proposed changes during field hearings conducted by the Department. In order to ensure that disabled persons are afforded an equal opportunity to respond to any proposed changes, we demand:

- A MINIMUM 120-DAY COMMENT PERIOD;
- 10 REGIONAL FIELD HEARINGS.

The changes in the existing §504 Coordination Guidelines currently under consideration by the Department of Justice represent a drastic departure from the long-sought-after and hard-won civil rights of disabled people. It is the responsibility of the current Administration to afford the affected class adequate opportunity to express its opposition to any changes. Your immediate attention to this matter is imperative.

Sincerely,

BRIEFING PAPER: PROPOSED CHANGES TO THE REGULATIONS IMPLEMENTING
PUBLIC LAW 94-142 - DoEd

Summary

In its effort to deregulate the Education for All Handicapped Children Act, PL 94-142, the Department of Education has drafted a set of proposed regulations. However, rather than eliminating federal regulations which create unnecessary burdens, the Department has written draft regulations which significantly reduce the likelihood that the Congressional goal of a free appropriate public education for every handicapped child will ever be realized by curtailing parental participation in the development and implementation of educational programs for handicapped children.

Because of the egregious record of state and local neglect of the education of handicapped children, Congress grounded its assurance in the creation of rights for parents to participate in the planning and monitoring of the children's education. The change the Administration makes in the draft regulations seriously undermines the ability of parents to fulfill their role.

- The essential first step in achieving an appropriate education for a handicapped child is an accurate evaluation. The proposed change in the regulations would result in less accurate information about a child's handicapping condition and learning needs.

- Furthermore, parents would have access to less information about their child and the school's action as a result of these regulations. At the very important Individualized Education Program (IEP) meeting following a child's first evaluation, no one need attend the meeting who is knowledgeable about the evaluation instrument used or the child's results.

When an agency initiates or refuses a change in a child's placement, it need no longer explain to the parents the options it considered nor the tests or evaluations the decision was based on.

When parents go to a hearing to contest an agency's action, they may hear the agency's reasoning and evidence for its action for the very first time.

- Parents trying to obtain an appropriate education for their children at an IEP meeting or at a hearing are faced with new vague standards which make their ability to advocate for their child's rights much more difficult.

- Handicapped children lose the right to be educated with non-handicapped children to the maximum extent appropriate if it is claimed that the child could be a "probable" disruption;
- Handicapped children lose their right to related services if it is claimed that a less expensive service provided less often is of "substantially" equal benefit.

In both cases, a parent confronted with professional educators would have a difficult time arguing that their child's right to appropriate education was violated.

- Finally, the handicapped child's right to an appropriate education might never arise because no timelines are established for IEP implementation.

The following is a brief review of some of the major adverse revisions contained in the Department of Education's proposed PL 94-142 regulations.¹

EVALUATIONS

Protections in evaluation procedures assure that children are accurately classified and appropriately placed. The Department of Education proposed regulations weaken the evaluation protections and greatly limit parent participation.

The proposed regulations remove the requirement that parental consent be obtained before conducting a pre-placement evaluation.² The burden shifts to the parents to show why the evaluation is unnecessary.

The proposed rule eliminates the requirement that the test be "validated" for the specific purpose for which it is used or that the test be administered by "trained personnel."³ The changes would permit a classroom teacher, school nurse or administrator to develop and administer evaluations.

The proposed rule limits the current requirement that "the evaluation is made by a multidisciplinary team or group of persons, including at least one teacher or other specialist with knowledge in the area of disability,"⁴ requiring a multi-disciplinary "approach" only for "children suspected of having severe, multiple, or complex disorders, including a specific learning disability."⁵ The requirement that a child be "assessed in all areas related to the suspected disability..."⁶ has been deleted entirely. These changes also increase the likelihood of misclassification. In addition, many needs of a child would go undetected. A mentally retarded child may be in need of additional services, such as physical or occupational therapy or speech therapy. The proposed rule does not require the school district to assess those needs.

¹ The existing regulations were codified at 45 CFR §121a.1 et seq. They are currently at 34 CFR §300.1 et seq. This memo refers to the old codification of the existing provisions in order to easily distinguish them from the current proposed regulations.

² 45 CFR §121a, 504(b)(i) The proposed rule also eliminates the requirement that consent be obtained before initial placement, §121a.504(b)(ii).

³ Compare 45 CFR §121a.532(a)(2)(3) with 34 CFR §300.158(d), "tests... must be properly and professionally evaluated" and "administered in conformance with instructions provided by the producers of the tests and materials."

⁴ 45 CFR §121a.532(e)

⁵ 34 CFR §300.158(g)

⁶ 45 CFR §121a.532(f)

The requirement that the IEP meeting must take place 30 days after the evaluation⁷ has been eliminated. The proposed regulations propose no new timeline. A child who is deemed to need special education could wait (and waste) several months before an IEP is even developed.

The proposed rule removes the requirement that a member of the evaluations team participate in the IEP meeting for a child who has been evaluated for the first time.⁸ A parent attending his child's first IEP meeting (and he may not even have consented to the evaluation) may have no one present who understands the test or the results to question or confer with.

The requirement that a child be evaluated "every three years or more frequently if conditions warrant or if the child's parents or teacher requests an evaluation"⁹ has been removed. The proposed rule provides for reevaluation "at intervals determined by the State educational agency, or more frequently if the agency is presented with substantial evidence that such a reevaluation is necessary in order to meet the child's educational needs."¹⁰ A child could remain inappropriately placed indefinitely under this provision.

While parents are required to present substantial evidence of the need for reevaluation, the right to obtain an independent evaluation at public expense¹¹ is taken away in the proposed rule. The proposed rule requires parents to pay for independent evaluations unless "a reviewing officer requests an independent educational evaluation as part of a hearing or review."¹² This provision discriminates on the basis of wealth.

NOTICE

The existing regulations require that written notice be provided whenever a school district proposes to initiate or change a child's identification, evaluation, or educational placement. The proposed regulations eliminate the requirement that this notice include "...a description of any options the agency considered and the reasons why those options were rejected",¹³ and "a description of each evaluation, procedure, test, record

⁷ 45 CFR §121a.344(b)

⁸ 45 CFR §212a.343(c)

⁹ 45 CFR §212a.534(b)

¹⁰ 34 CFR §300.141

¹¹ The current regulations give parents the right to obtain an independent evaluation at public expense unless the public agency initiates a hearing to show that its evaluation is appropriate. 45 CFR §121a.503(b).

¹² 34 CFR §300.144(d)

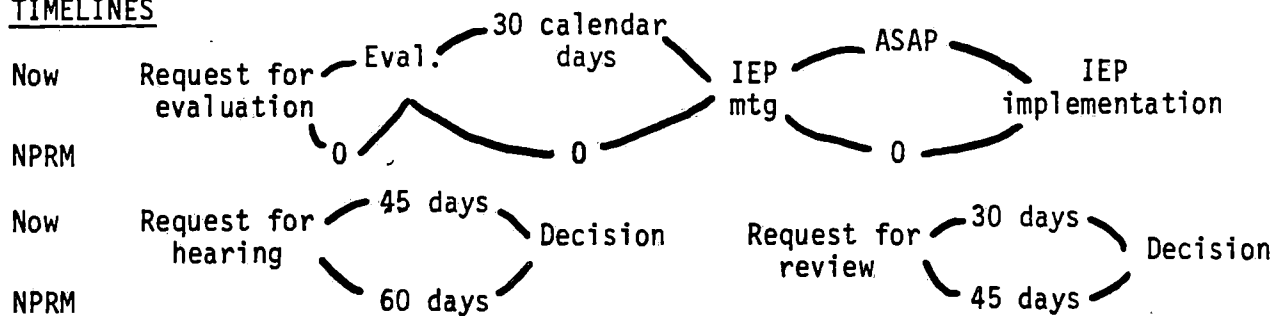
¹³ 45 CFR §121a.505(a)(2)

or report the agency uses as a basis for the proposal or refusal."¹⁴ Instead, the school district may include "any other information deemed relevant by the public agency to assist the parent in understanding the agency's proposal or refusal."¹⁵

DUE PROCESS

If a parent chooses to initiate a due process hearing to contest the school district's action, the parent is still not entitled to know the basis of the school district's decision until the time of the hearing. Presently, either party to a hearing has the right to "prohibit the introduction of any evidence at the hearing that has not been disclosed to that party at least five days before the hearing."¹⁶ The requirement has been eliminated.

TIMELINES



RELATED SERVICES

Currently, related services must be tailored to the individual needs of the child. The proposed rule provides:

34 CFR §300.4(10)(ii) In determining whether a service is required to assist a handicapped child to benefit from special education, in developing the child's individualized educational program, a public agency is not precluded from imposing reasonable limitations related to

- (A) The level, frequency, and duration of services required;
- (B) The qualifications of the providers of those services;
- (C) The cost of those services, where they are selected from among alternatives that would provide substantially equal educational benefit; and

¹⁴45 CFR §121a.505(a)(3)

¹⁵34 CFR §300.146(a)(3)

¹⁶45 CFR §121a.508(a)(3)

(D) Services required in light of the educational placement appropriate for the child...¹⁷

A school district might decide that is "reasonable" to place a ceiling of two times a month on speech therapy or that an aide can provide the speech therapy. Determining whether a service will provide "substantially equal" educational benefit is an unworkable standard and runs contrary to the intent of PL 94-142.

LEAST RESTRICTIVE ENVIRONMENT

The proposed regulations remove the requirement that a child be educated as close to the child's home as possible.¹⁸ This change encourages segregation and the use of regional centers for the education of handicapped children. The proposed rule also eliminates the current requirement that a school district provide a "continuum of alternative placements."¹⁹ The continuum of alternative placement provision assures that placement not be limited to what is currently available. For example, many school districts only have segregated settings available for children classified as trainable mentally retarded. The continuum of alternative placement provision requires the school district to begin to develop alternatives, such as special classes on regular school sites.²⁰

The proposed rule also allows a school district, in determining the least restrictive alternative, to "consider an actual or probable substantial and clearly ascertainable disruption of the educational services provided to other children."²¹ This provision is subject to abuse. Stereotypes could result in a determination that "probable disruption" would result from the participation of a mentally retarded or severely handicapped child.

¹⁷The proposed regulations also provide that a school district is not required to provide "life sustaining procedures that can be provided outside the normal school day, must be performed under sterile conditions, must be administered by specially-trained, licensed health care professionals or entail significant risk of illness or more than minimal injury." 34 CFR §300.4(10)(ii). This provision could result in the exclusion or segregation of children in need of these services. For example, the right of a child to receive clean intermittent catheterization, Tatro v. State of Texas, 625 F.2d 557 (5th Cir., 1980), may be jeopardized.

¹⁸45 CFR §121a.552

¹⁹45 CFR §121a.551

²⁰34 CFR §300.161(c)(2)

²¹Ibid.

Public Law 94-142 and Section 504
and Position of
The President's Committee on Mental Retardation

WHEREAS, disabled children and adults have historically been denied the right to obtain a meaningful education, appropriate vocational training, and access to basic human services, and have been relegated to a role of dependency and a loss of human dignity; and

WHEREAS, The Education of All Handicapped Children Act, Public Law 94-142, was passed into law to guarantee disabled children a right to a free public education provided in conjunction with specific related services which would allow them to have an equal educational opportunity; and

WHEREAS, Section 504 of the 1973 Rehabilitation Act guarantees that as these disabled children grow into adulthood, they will be provided with equal access to the educational, training, employment, social services, transportation and housing services available to the nondisabled; and

WHEREAS, the implementation of both of these laws through federal regulations over the last five years has resulted in greater opportunities for meaningful educational programs for over 4 million disabled children throughout the country, and uncounted numbers of disabled adults from lives of total dependency and low self-esteem to productive lives through increased employment and training opportunities and expanded avenues to social services and community life; and

WHEREAS, the premise that some disabled persons would not be able to benefit from meaningful educational and training opportunities, and that a determination should be made regarding the extent to which disabled people would either benefit from or contribute to the operations of a program in a manner which would be "socially beneficial" to all parties, speaks to age-old prejudices against the disabled, denies them basic human dignity, and is antithetical to the concept of equal citizenship; and

WHEREAS, these two laws were passed because similar protections were not and are not available through existing states' statutes;

THEREFORE, BE IT RESOLVED that the President's Committee on Mental Retardation reaffirms their strong commitment to retaining the existing laws and regulations pertaining to Public Law 94-142 and Section 504 in substantially their present form, and encourages the President to take a positive and public stand to halt all efforts to change these laws through regulatory and legislative reform that would adversely affect mentally retarded citizens. Through these laws, the way has been cleared for preparing a large segment of our society to moving from lives of dependency to greater independency by becoming tax-paying citizens. Public Law 94-142 and Section 504, and their implementing regulations constitute an investment, rather than a burden, to society.

M E M O R A N D U M

TO: 504 Coordinators and Network
 FROM: Arlene B. Mayerson, Staff Attorney
 RE: Hendrick Hudson Central School District v. Rowley

WHAT WERE THE FACTS INVOLVED IN THE ROWLEY CASE?

Amy Rowley, a deaf girl, attended an integrated elementary school. An IEP was prepared for Amy during the Fall of her first grade year. The IEP provided that Amy should be educated in a regular classroom, should continue to use an FM hearing aid, and should receive instruction from a tutor for the deaf for one hour each day and from a speech therapist for three hours each week. Amy's parents requested that a sign language interpreter be provided for all academic classes.

When the request for an interpreter was denied, the Rowley's instituted administrative procedures under PL 94-142 to challenge the school district's decision. The hearing officer ruled in favor of the school district, finding that Amy was achieving educationally and socially without an interpreter.

Pursuant to PL 94-142's provision for judicial review, the Rowley's filed suit in federal district court. The district court found that Amy "is a remarkably well-adjusted child" who has "developed an extraordinary rapport" with her teachers.* It also found that "she performs better than the average child and is advancing easily from grade to grade.** However, the district court also found that Amy "understood considerably less (59%) of what goes on in class than she would if she were not deaf", and therefore was "not learning as well academically"*** as she would with a sign language interpreter. The district court held that Amy was not receiving a "free appropriate public education" (FAPE) because without a sign language interpreter she was denied "an opportunity to achieve her full potential commensurate with the opportunity provided to other children."**** The federal Court of Appeals for the Second Circuit affirmed the district court's decision.***** The school district sought and was granted review before the U.S. Supreme Court.

WHAT WERE THE ISSUES BEFORE THE SUPREME COURT IN ROWLEY?

The Supreme Court considered two issues: What is meant by the PL 94-142 requirement of a "free appropriate public education" (FAPE), and, what is the role of the state and federal courts in reviewing state educational agency decisions.

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HOW DID THE COURT DEFINE FAPE?

The court stated:

According to the definitions contained in the Act, a "free appropriate public education" consists of educational instruction specially designed to meet the unique needs of the handicapped child, supported by such services as are necessary to permit the child "to benefit" from the instruction. Almost as a checklist for adequacy under the Act, the definition also requires that such instruction and services be provided at public expense and under public supervision, meet the State's educational standards, approximate the grade levels used in the State's regular education, and comport with the child's IEP. Thus, if personalized instruction is being provided with sufficient supportive services to permit the child to benefit from the instruction, and the other items on the definitional checklist are satisfied, the child is receiving a "free appropriate public education" as defined by the Act.

The court also stated:

We therefore conclude that the "basic floor of opportunity" provided by the Act consists of access to specialized instruction and related services which are individually designed to provide educational benefit to the handicapped child.

HOW DID THE COURT DECIDE WHETHER AMY WAS RECEIVING AN FAPE?

After defining the applicable standards, the Court recognized that "the determination of when handicapped children are receiving sufficient educational benefits to satisfy the requirements of the Act presents a more difficult question." The Court stated:

We do not attempt today to establish any one test for determining the adequacy of educational benefits conferred upon all children covered by the Act. Because in this case we are presented with a handicapped child who is receiving substantial specialized instruction and related services, and who is performing above average in the regular classrooms of a public school system, we confine our analysis to that situation.

The Court reasoned that when a child is being educated in the

regular classrooms of a public school system, "the system itself monitors the educational progress of the child. Regular examinations are administered, grades are awarded and yearly advancement to higher grade levels is permitted for those children who attain an adequate knowledge of the course material. The grading and advancement system thus constitutes an important factor in determining educational benefit."

Using the above reasoning, the Supreme Court held that Amy was receiving an FAPE without a sign language interpreter:

...the District Court found that the "evidence firmly establishes that Amy is receiving an adequate education, since she performs better than the average child in her class and is advancing easily from grade to grade." 483 F.Supp at 534. In light of this finding, and of the fact that Amy was receiving personalized instruction and related services calculated by...school administrators to meet her educational needs, the lower courts should not have concluded that the Act requires the provision of a sign language interpreter.

WERE OTHER PROVISIONS OF PL 94-142 AFFECTED BY THE SUPREME COURT DECISION?

The Court's decision did not affect the basic provisions of PL 94-142.

a) Each child must be given evaluations to determine the need for special education and related services.

b) Each child must have an IEP (individualized education plan).

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d) Related services must be provided to enable the child to benefit from his/her educational program. (The Court held that Amy did not need a sign language interpreter to benefit from her educational program.)

e) Disabled children must be educated with non-disabled children to the maximum extent appropriate.

f) Each child's IEP must be reviewed at least annually.

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or the provision of a free appropriate public education to the child.

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HOW DOES ROWLEY AFFECT OTHER DISABLED CHILDREN?

Again, as noted above, the Supreme Court explicitly stated in Rowley:

Because in this case we are presented with a handicapped child who is receiving substantial specialized instruction and related services, and who is performing above average in the regular classrooms of a public school system, we confine our analysis to that situation.

(Emphasis added)

Each child must still receive "personalized instruction with sufficient support services to permit the child to benefit educationally from that instruction." The IEP must still be based on the unique needs of the individual child.

If the child is in a regular classroom, above average performance and passing from grade to grade will be considered very significant factors in determining whether the child is benefitting from education.* Many disabled children will need supportive and related services to reach this level of achievement. Indeed, many deaf children will require interpreters in order to advance to higher grade levels. Amy was an excellent lip-reader, was doing well in class without an interpreter and the school district was providing her with other supportive services. The interpreter was necessary for Amy to maximize her potential. The Court held that PL 94-142 requires an "appropriate" education, not a potential-maximizing education.

* The Court did state, however, that "We do not hold today that every handicapped child who is advancing from grade to grade in a regular public school system is automatically receiving a 'free appropriate public education.'"

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The development of a comprehensive IEP, with goals and objectives which accurately reflect the child's potential, becomes all the more important. Achievement toward the IEP goals will be used to determine whether the child is "benefiting" from his/her educational program.

WHAT IS THE ROLE OF FEDERAL AND STATE COURTS IN REVIEWING STATE ADMINISTRATIVE DECISIONS?

The Supreme Court specifically rejected the school district's arguments that courts could only assure that PL 94-142's procedures were followed. The Court reiterated the power of the courts to make "independent decisions based on the preponderance of the evidence." In summary, the Court stated that a court's inquiry is two-fold.

First, has the State complied with the procedures set forth in the Act? And second, is the individualized educational program developed through the Acts procedures reasonably calculated to enable the child to receive educational benefits.

It should be noted that the Supreme Court cautioned the lower courts to avoid imposing their own view of preferable educational "methods" upon the States. Nonetheless, the federal courts do retain the power to review the substance of the state's proposed educational program and to order additional services if that program is not individually designed to provide each child meaningful access to education.

CAN A SCHOOL DISTRICT PLACE A CHILD IN A SEGREGATED SETTING RATHER THAN PROVIDING THE SERVICES HE/SHE NEEDS TO SUCCEED IN A "MAINSTREAMED" CLASSROOM?

The Supreme Court explicitly affirmed each child's right to be educated with non-handicapped children to the maximum extent appropriate. The Court quoted the statutory provision which assures that "removal of handicapped children from the regular educational environment occurs only when the nature or the severity of the handicap is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily." Supplementary aids and services must be pro-

vided if they enable a disabled child to participate in regular education.

CAN A SCHOOL DISTRICT DENY A SERVICE BASED ON THE COSTS OF THE SERVICE?

Notably, the Supreme Court does not refer to the cost of providing interpreter services even though the school district stressed this factor in its briefs before the Court. A school district must still provide those services which allow a child to benefit from her/his education, regardless of the costs involved.

QUESTIONS AND ANSWERS ABOUT THE ROWLEY DECISION

Prepared by the National Center for
Law and the Deaf

Q. Does the Rowley decision mean deaf children cannot get interpreters in public schools?

A. No. The Court only said that Amy Rowley does not need an interpreter. A deaf child who depends on an interpreter in order to benefit from his/her education will get one. If the child's Individualized Educational Plan (IEP) requires an interpreter, it must be provided.

Q. How will deaf children get the necessary services that they need in classrooms?

A. If the school and parents agree that the child needs an interpreter, a qualified teacher, or a total communication program, the child will get one. If the school disagrees, the parents must prove that the child will not benefit from school without necessary services. For example, parents could show that the child would not do well in school without an interpreter, or that the child would not be able to understand the teacher well enough to learn, without a total communication program.

Q. Why did the Supreme Court rule that the school did not have to provide and interpreter for Amy?

A. The court recognized that Amy was exceptional. Amy was an excellent lipreader, she was doing well in class without an interpreter, and the school was providing her with other support services. For example, they were providing her with an amplifying system, a certified teacher of the deaf for one hour a day, and a speech therapist for three hours a week. The court held the school was already providing her with an appropriate education.

Q. How does the Court define appropriate education?

A. Although the Court did not describe what is an appropriate education in all cases, it said that schools must provide services which are individually designed to allow each handicapped child to benefit from his/her education. One of the things to be considered is whether the child passes from grade to grade. But that is not the only thing to be considered.

Q. Does the decision mean handicapped children do not have a right to the best education possible?

A. The law never required schools to provide the best education possible. It only required schools to provide an "appropriate" education.

Q. Does the decision hurt bright handicapped children?

A. Yes. If they are doing well in school (above average) without specific support services, then it will be hard to convince the state to provide new support services. If they already have some kind of support services written into their IEPs, then these services should continue.

Q. Does the Rowley case weaken the Education for all Handicapped Children's Act (PL 94-142)?

A. No. The Court upheld the basic parts of the law.

a. Each handicapped child must still have an individualized educational plan.

b. Sufficient support services must be provided so the child may benefit from his/her education.

c. The parents do not have to pay for the support services or the IEPs.

d. Parents are to share in the planning and development of state plans and the child's IEP.

e. If parents are not satisfied with the child's IEP, they can appeal and ask to have it changed.

f. If parents are not happy with the results of the appeal and hearings, they can still go to court and have a judge decide if the IEP is fair.

Q. Does the decision weaken parent's rights?

A. No, it actually strengthens them. The Department of Education has been trying to stop parents from being involved with IEPs and state plans. The Court held that PL 94-142 requires that parents be involved in such planning and programs.

Q. Does the Rowley decision mean that colleges, hospitals, and courts do not have to provide interpreters for deaf people who need them?

A. No. Colleges, hospitals and other places receiving federal money must provide interpreters because of Section 504 of the Rehabilitation Act of 1973. Section 504 was not involved in the Rowley case. The Rowley case was about PL 94-142, a different law which applies only to public school.

Justices See a Limit to Services Schools Must Offer Handicapped

By Charles R. Babcock
Washington Post Staff Writer

Ruling for the first time on the controversial question of how much special assistance a public school district must make available to a handicapped pupil, the Supreme Court held yesterday that federal law requires school boards to provide some services for the handicapped, but not all those needed to "maximize" a student's learning potential.

The 6-to-3 decision, written by Justice William H. Rehnquist, said that under the federal Education for All Handicapped Children Act of 1975, Amy Rowley, an 11-year-old deaf girl, is not entitled to a free sign language interpreter as ordered by a lower court.

The family's attorney, Michael A. Chatoff, who is deaf and read the justices' questions in oral argument with the aid of a computer, described Amy as a bright child who had been progressing well in her classes by reading lips. But the interpreter was needed, he told the court, so Amy would have a chance to reach her full potential, the same as nonhandicapped students. The lower courts agreed and ordered the New York state school she attends to provide the interpreter.

The decision was the Supreme Court's first review of the act, which assures that states provide a "free appropriate public education" to students with disabilities. Gwen Gregory, deputy legal counsel for the National School Boards Association, whose members have been fighting lawsuits under the act, said the decision limits a board's duties and also limits the federal courts' ability to "second guess" local educational decisions.

Al Pimental, executive director of the National Association for the Deaf, said the ruling was "very negative" and accused the majority of "making the law, rather than interpreting it."

Nancy Rowley, Amy's mother, said yesterday at her home in Montrose, N.Y., that "it isn't fair. She was ready to be equal. She has the right to progress."

The case turned on the court's interpretation of what Congress meant by "free appropriate public education." Rehnquist said that in passing the 1975 law, Congress "sought primarily to make public education available to handicapped children. But in seeking to provide such access to public education, Congress did not impose upon the states any greater substantive educational standard than would be necessary to make such access meaningful."

He said Congress recognized it couldn't guarantee any particular educational outcome for the 4 million students served under the law. "Thus, the intent of the act was more to open the door of public education to handicapped children on appropriate terms than to guarantee any particular level of education once inside," he wrote.

States meet the act's requirements "by providing personalized instruction with sufficient support services to permit the child to benefit educationally from that instruction," Rehnquist added. There is no requirement in the law, he said, that the services provided "be sufficient to maximize each child's potential" with the opportunities provided other children.

The decision in *Hendrick Hudson District Board of Education vs. Rowley* also warned lower courts to "be careful to avoid imposing their view of preferable educational methods upon the states."

The act contains strict procedural protections for parents, which Rehnquist said showed that Congress meant "adequate compliance with prescribed procedures will in most cases assure much, if not all, of what Congress wished in the way of substantive content in an IEP [individualized educational program]."

Chief Justice Warren E. Burger and Justices Lewis F. Powell Jr., John Paul Stevens, Harry A. Blackman and Sandra Day O'Connor joined Rehnquist.

Blackman said he felt the law did require equal opportunity for handicapped children, but that the school board in the Rowley case had tried to provide it.

Justice Byron R. White wrote a dissent, joined by William J. Brennan Jr. and Thurgood Marshall, in which they accused the majority of misreading the legislative history of the law. Providing Amy Rowley with some educational benefits is not enough, White argued. He said the majority seemed to be saying "a teacher with a loud voice" would be enough to satisfy the law's requirements.

Pat Wright of the Disability Rights Education and Defense Fund Inc. said the handicapped education law was drafted so strongly that the ruling "couldn't take away the rights of disabled school children and their parents." She said her group "is concerned the decision will be interpreted as a setback" so "we will be vigorously monitoring the actions of school districts and the Reagan administration."

THE EROSION OF SECTION 504
THE CIVIL RIGHTS MANDATE FOR DISABLED PEOPLE

Section 504 of the Rehabilitation Act of 1973 is under heavy attack by the Reagan Administration. If successful, it would undermine all disabled people's right to public transportation; threaten protections against discrimination in education to disabled people; remove any protection against employment discrimination; and deny equal access to health and social service programs receiving federal assistance.

Section 504, the first major revision of disability policy since 1920, was enacted as the key national civil rights mandate conferring constitutional protections of equality of opportunity upon a class of people perceived as "handicapped." It was a statement that organized society would take steps to eliminate the historic patterns of exclusion and discrimination and extend the privileges of full and equal citizenship to disabled people. Four years after enactment of Section 504, the Department of Health, Education, and Welfare (DHEW) issued its 504 implementing regulations and inter-agency guidelines. They were developed after careful evaluation of public comments, public hearings, consideration of administrative cost burdens to recipients of federal assistance, and a clear understanding of the Congressional intent to end discrimination and exclusion of disabled people from the mainstream of society. The 504 regulations were finally signed and issued after Congressional requests, successful litigation, petitions, and peaceful assemblies and civil disobedience by disabled people. They were in force two years when court and administration actions began to signal a rapid retreat from this hard-won civil rights mandate.

- o The Administration rescinded the Department of Transportation 504 regulations that provided for bus and fixed rail access, and re-issued old regulations which do not. This action was taken in haste and without regard to its responsibility to provide equal treatment to disabled people under the Urban Mass Transportation Act and Federal Aid Highways Act; without consideration of remaining Section 504 mandates and without adequate notice for comment by those affected by the changes.

- o The Office of Revenue Sharing issued revised Section 504 regulations which violate the existing guidelines by excluding transition plans and self-evaluation requirements. Again, adequate notice for comment was not provided.

- o The Department of Education has issued internal memos restricting investigation in specified areas of Section 504 (employment, auxiliary aids, and others); this conflicts with existing 504 mandates and interagency guidelines. The process is occurring without adequate notice and opportunity for disabled people to comment.

In the face of these actions, the Department of Justice has failed to enforce its 504 mandate. Further, it is reviewing the 504 Inter-Agency Guidelines for "burdensome" restrictions, a process that could drastically limit protections in employment; provide for means-income tests; limit accommodations and modifications on the basis of perceived economic costs; define qualified handicapped person in terms of perceived degree of impairment and replace the equal opportunity requirement with a requirement for "substantially" equal opportunity. This will result in a civil rights statute that will protect only those persons who are able to meet all program criteria in spite of the existence of handicap, i.e., those disabled persons least in need of protection of their civil rights.

BLOCK GRANTS--FROM LITTLE TO LESS

The disabled community depends on the interlocking relationship of benefits, services, training opportunities, and communications and physical access to participate equally and fully in the community. Although funding for rehabilitation services and independent living programs has not yet been reduced substantially, their effectiveness is severely undercut when concomitant ancillary services and programs are withdrawn.

Severely disabled persons can expect a reduction in services over the next years because local communities cannot provide essential supplementary and back-up services which provide access to the community at large. Without the life-support systems (e.g., accessible housing, attendant care), accessible public transit, and training opportunities, employment for the disabled young adult becomes a fantasy. A low-income disabled person who is a member of a racial or ethnic minority is likely to fall through the safety net into a nursing home or state hospital.

The continued integration of low-income severely disabled people into their communities has been further threatened by the consolidation of federal programs into block grants. Proposed by the Reagan Administration and adopted by Congress, the block grants make the states responsible for administering and allocating funds. Many disabled persons rely on community-based support services to maintain an independent, non-institutionalized life style. Previously, the federal government assured implementation of policies in health, education and social services, but, under the block grant program, the states decide what programs should be funded and at what level.

Facing a drastic reduction in funding for such programs next year, the states must decide which programs to cut and which populations to stop serving. This sets up a potential for friction among equally needy groups and a tendency to compete for rapidly dwindling resources. Groups with special needs must form coalitions and support each other's goals in order to prevent the block granting process from threatening the solidarity of the low-income community.

BUDGET PROJECTIONS FOR DISABILITY-RELATED PROGRAMS

The following areas are likely targets for upcoming budget slashing. It is difficult to measure the effect on individual disabled people; however, a 25% to 35% (as reflected in the right hand column) cut in any area, coupled with the need for all poor and disenfranchised persons to fight for program funding on the state level leaves the 35,000,000 disabled persons, including children, the elderly and racial and ethnic minority group members, 25%-35% less able to live with dignity and freedom of choice.

	FY 1981 (pre- recis- sion	FY 1982 Authori- zation	House Appropri- ations Committee	Senate Labor, HHS Ed. Sub- committee	Adminis- tration Propo- sals*	Percent of Proposed Re- duction from FY 1981
<u>Special Education</u>						
Programs include PL 94-142 (The Education for all Handicapped Children Act) state grants, pre-school incentives and Title I set aside for the Handicapped.						
	1112.0	994.8	1092.125	1077.625	733.66	34%
<u>Vocational Rehabilitation</u>						
Programs include State Grants, Service Projects and Training						
	912.6	954.5	905.8	898.3	797.2	12%
<u>Independent Living</u>						
Independent Living Programs (ILPs) have been the key to integration of disabled adults into their home communities. ILPs, in most states, provide crucial direct services to community residents such as attendant referral, transportation, housing referral, financial advocacy, counseling and transportation						
	18.0	19.4	18.0	18.0	11.9	34%
<u>Developmental Disabilities</u>						
Approximately 2.2% of the population of the U.S. are developmentally disabled (disabled since birth or early childhood, or are functionally disabled according to the new federal definition). Services and programs are keyed to serving this large, specialized population and, although presently appear in tact, would be severely diminished if the administration achieves its new cuts.						
	628.0	491.0	485.0	450.0	421.1	33%
<u>Title XX Social Services</u>						
Among other programs, Title XX supports attendant care programs in some states. These are critical, life support services without which severely disabled persons cannot live independently in the community.						
	2.9	2.4	2.4	2.4	1.9	34%

OTHER VITAL SERVICES AND PROGRAMS CUT OR ELIMINATED

Veterans Administration: While Veterans benefits have gone up, \$16 million slated for Veterans Outreach Centers in rural areas will not be spent. The Technical Assistance program, which gave assistance to organizations serving veterans, has been abolished.

Job Training Programs: CETA cuts have eliminated all public service employment and the program is doing classroom training only. The VISTA program has been severely restricted. This program is the only one that allows disabled volunteers the opportunity to gain job experience, while keeping life supporting SSI benefits. VISTA, in addition to providing disabled people with job experience, also provided staff people for community service centers. The Youthwork Project, which provides independent living skills and job placement to disabled minority youth, is ending.

Low Income Housing for Disabled Persons: The HUD Section 8 rental assistance program was cut from 254,550 units in FY 1981 to 153,000 in FY 1982. In addition, families are now required to pay 30 percent (rather than 25 percent) of their income before the subsidy becomes effective.

Low Income Energy Assistance Program: The Low Income Energy Assistance Program (LIEAP) which helps low income persons pay utility bills, has been cut almost in half. Moreover, the states have now been relieved of the obligation to give priority in program participation to the elderly and disabled whose very lives may depend on this assistance.

Disabled persons must fight with other poor and disenfranchised groups to combat these life and freedom threatening budget cuts. We must educate ourselves and others about the extent of the reductions both now and for the years ahead.

* These figures were calculated using the President's March 10th proposal of a 25% reduction from FY 1981 levels and adding his requested additional 12% reduction.

Prepared by the Disability Rights Education and Defense Fund, Inc., 2032 San Pablo Avenue, Berkeley, California 94702. If you wish further information, please contact us (415) 644-2555.

M E M O R A N D U M

TO: 504 Coordinators and Network
 FROM: Arlene B. Mayerson, Staff Attorney
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The Rowley decision is most applicable to disabled children in "mainstreamed" public school classes. If a child is passing, it is assumed that s/he is benefiting. Many disabled children attend special education classes which are not graded. In these instances, the child's individualized goals and objectives contained in the IEP are the only relevant measuring stick. Unlike regular education, there is no generalized goal, i.e., passing, applicable to all children in the class. Any service which assists the child in reaching his/her individualized goals must continue to be provided.

The development of a comprehensive IEP, with goals and objectives which accurately reflect the child's potential, becomes all the more important. Achievement toward the IEP goals will be used to determine whether the child is "benefiting" from his/her educational program.

WHAT IS THE ROLE OF FEDERAL AND STATE COURTS IN REVIEWING STATE ADMINISTRATIVE DECISIONS?

The Supreme Court specifically rejected the school district's arguments that courts could only assure that PL 94-142's procedures were followed. The Court reiterated the power of the courts to make "independent decisions based on the preponderance of the evidence." In summary, the Court stated that a court's inquiry is two-fold.

First, has the State complied with the procedures set forth in the Act? And second, is the individualized educational program developed through the Acts procedures reasonably calculated to enable the child to receive educational benefits.

It should be noted that the Supreme Court cautioned the lower courts to avoid imposing their own view of preferable educational "methods" upon the States. Nonetheless, the federal courts do retain the power to review the substance of the state's proposed educational program and to order additional services if that program is not individually designed to provide each child meaningful access to education.

CAN A SCHOOL DISTRICT PLACE A CHILD IN A SEGREGATED SETTING RATHER THAN PROVIDING THE SERVICES HE/SHE NEEDS TO SUCCEED IN A "MAINSTREAMED" CLASSROOM?

The Supreme Court explicitly affirmed each child's right to be educated with non-handicapped children to the maximum extent appropriate. The Court quoted the statutory provision which assures that "removal of handicapped children from the regular educational environment occurs only when the nature or the severity of the handicap is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily." Supplementary aids and services must be pro-

vided if they enable a disabled child to participate in regular education.

CAN A SCHOOL DISTRICT DENY A SERVICE BASED ON THE COSTS OF THE SERVICE?

Notably, the Supreme Court does not refer to the cost of providing interpreter services even though the school district stressed this factor in its briefs before the Court. A school district must still provide those services which allow a child to benefit from her/his education, regardless of the costs involved.

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AN ANALYSIS OF THE REAGAN ADMINISTRATION'S PROPOSED "EDUCATION OF THE HANDICAPPED AMENDMENTS OF 1982"

SUMMARY

The Administration has written a very dangerous -- because it is a seemingly "reasonable" -- bill which eviscerates P.L. 94-142's assurance of a "free appropriate public education" (FAPE) and virtually eliminates the power of any party to enforce the minimal protections it retains. The terminology and definitions remain substantially the same (with a few exceptions) but the mandates and mechanisms for implementing the services and protections are so qualified that they become almost meaningless.

Under the proposed law, the substance of a free appropriate public education changes radically, first in the assurance itself. Current law requires that

[t]he state has in effect a policy that assures
all handicapped children the right to a free
appropriate public education. [Emphasis added.]

Proposed law eliminates the individual right and requires assurances that

[t]he State has in effect a policy that assures
that a free appropriate public education is
available for all handicapped children ... [between
3 and 21, unless state law provides otherwise].
[Emphasis added.]

By framing the requirement this way, any inquiry into compliance begins with the question what programs are available, rather than what is appropriate for an individual child. Implicit in the new language is a less individualized approach to providing special education.

Furthermore, under the proposed law the cost of education and services may be considered by a local educational agency (LEA) when "choosing between placements of substantially equal benefit to a handicapped child." An LEA evaluation of "substantially equal benefit" is a subjective judgment which advocates would have difficulty overturning except in the most egregious situations.

The specific mechanisms which are used to create FAPE and the elements which comprise it are very different under the Administration bill.

- FAPE may no longer be interpreted to require education in excess of the regular school year.
- The individualized education program (IEP) is eliminated. States need only provide "individualized educational planning for each handicapped child." The proposed law defines it no further.
- Handicapped children are required to be educated with non-handicapped children only "to the extent appropriate" (deleting the word "maximum," which appears in the existing law), "taking into account the educational needs of both handicapped and non-handicapped children." The educational agency is no longer restricted to segregating the child

only when the nature or severity of the handicap is such that education in regular classes with the use of supplemental aids and services cannot be achieved satisfactorily.

This language from P.L. 94-142 is deleted entirely.

- Handicapped children are no longer protected from being classified through the use of testing and evaluation methods and materials which discriminate, but only from those which are

selected and administered in a manner intended to be discriminatory on the basis of race, color, or national origin. [Emphasis added.]

In other areas of the law, "intent" has been very difficult to prove. As a result of this change, courts could hear evidence which proved that certain tests discriminated against children and yet be unable to prohibit their use unless "intent" to discriminate were also proved.

LEAs are no longer prohibited from using only one procedure to determine an appropriate program for a child.

- The state is responsible for "coordinating the provision of any necessary related services," but other provisions appear to undercut the ability to argue that any services are necessary. Related services are no longer necessary for maximum integration of handicapped children with non-handicapped. Their cost may be considered when choosing between placements of "substantially equal benefit." And there is no forum or opportunity for parents to request services since the IEP is no longer required.

Weak as these rights and protections now appear, they are even less meaningful in view of the changes in the enforcement in the law. Should a state or LEA fail to comply with even these minimal requirements, little can be done.

Although parents have many of the same due process rights under the proposed law as they now have, the value of these rights is clearly in jeopardy since the administrative hearings may be conducted by schoolboards, in many cases the very bodies setting the policies parents are challenging. The proposed law also provides for mediation or arbitration if all parties agree, but there would seem to be little incentive for school boards to agree to arbitration when they can make the decisions themselves in hearings.

Should parents take their grievances to court, courts are restricted in their review. They are limited to considering the record from the administrative hearing and must affirm the administrative decision if it is supported by substantial evidence.

(Under existing law courts must hear additional evidence at the request of any party and must base their decision on the preponderance of the evidence.)

And throughout this process of review students may be forced to attend the very placements or programs their parents are challenging as inappropriate and/or harmful to their learning and development. P.L. 94-142 now provides that while a challenged practice is being reviewed, students will remain in their current placements or be admitted to a school unless both the state or the LEA and the parents agree otherwise. The proposed amendments give states the authority to change that by adding to existing language the qualification, "except to the extent that state law specifically provides to the contrary."

Should the federal government somehow learn of a problem (an unlikely occurrence since it is required to collect little information) and should it then wish to take action against a state or LEA, it must go through a lengthy procedure which presumes the state to be in compliance and prevents the Secretary from withholding funds until a final decision is reached if the state merely files a petition for review. Under current law the Secretary is presumed correct and may withhold money pending the outcome of the review. (The only exception to the proposed process occurs when the Secretary substracts money from state or local grants to pay for services in private schools in these jurisdictions. In that instance, as is true under P.L. 94-142 generally, the Secretary is presumed to be correct and the money is withheld pending the final outcome.)

Should a state learn of LEA non-compliance (once again, somewhat unlikely since the state is required to collect little or no information which would reveal non-compliance) and should it desire to make the LEA comply with the law, its only mechanism for enforcement appears to be in the initial distribution of funds.

State power over LEAs is almost absolute in terms of funds allocations. It may distribute 75% of its funds to LEAs in any manner it "determines is consistent with meeting the educational needs of handicapped children." Since the money flows to the state and not to the state educational agency, whatever distribution "formula" a state chooses to use may be subject to the political considerations of the state legislative branch. This state discretion also creates a situation in which all the various handicapped populations covered by the proposed amendments must compete with each other for ever more important and shrinking federal funds. Under existing law preschool-aged handicapped children and the very severely handicapped in institutions receive special money under separate programs. Under the proposed consolidation they will compete with the mentally and physically handicapped populations in public schools and handicapped children in private schools, the only population to benefit from a strengthened service mandate in this proposed law.

The Administration has succeeded in giving state and local educational agencies essentially unfettered discretion in the education of handicapped children -- even while retaining the appearance of specific federal protections. The need for and importance of the "Education for All Handicapped Children Act" are documented by the

background and history of P.L. 94-142. The specific changes proposed and their effect on handicapped children are discussed in the section-by-section analysis which follows. Careful analysis and explanation of the Administration's legislation will be necessary to ensure that the proposed amendments do not become the law.

BACKGROUND AND HISTORY OF P.L. 94-142

P.L. 94-142 was the culmination of nearly ten years of legislation. In response to states' widespread failure to provide public education to millions of children, Congress had progressively increased federal responsibility to guarantee appropriate educational services to the nation's handicapped children.

Federal involvement in education for handicapped children began in 1966. Congressional hearings revealed that fully two-thirds of the nation's handicapped children were either totally excluded from school or were sitting idly in regular classrooms, their special needs largely ignored. On the basis of these findings, Congress established a program of grants to the states to encourage both development of new special education programs for handicapped children and improvement of existing services. Four years later, in 1970, this program was expanded and federal funding for special education was increased.

Congressional concern was heightened between 1971 and 1973 by a series of court cases filed by handicapped children and their parents, seeking to establish a right to equal educational opportunity. The findings of the courts demonstrated that wholesale exclusion of handicapped children from schools and neglect of those in school remained a serious national problem.

Early in 1973, Congress began nearly a year and a half of hearings. More than 200 witnesses testified about the harm being done both to handicapped children and to society by the states' failure to provide these children an appropriate education. These witnesses included parents, teachers, school principals and superintendents, school board members, state and local officials, special education experts and other professionals expert in the care and education of handicapped children. They testified about large numbers of children denied many critical services.

The testimony described the educational neglect of children with all types of handicapping conditions, both severe and mild. It revealed that none of the states in which hearings were held was providing the broad range of services required to meet the varied needs of these handicapped children. Hearings were held in a number of states that had enacted state laws establishing a right to education for handicapped children. Yet even in these states, the testimony showed that substantial numbers of handicapped children continued to be denied appropriate services. Some children were placed on waiting lists, some children were excluded from school completely because services were unavailable and still others were placed in existing programs with little regard for their special individual needs.

Extensive testimony of both parents and educators focused on the wide range of services needed to educate appropriately these special children. The service needs discussed in the hearings included, inter alia, specialized diagnostic and evaluation services, speech therapy and communication-skills training, sign-language interpretation, vocational training, specialized tutoring programs, behavior modification programs, psychological counseling, self-help and self-care skills training programs and specially equipped resource rooms.

Figures ultimately adopted as congressional findings estimated that more than one million handicapped children were excluded entirely from public school and more than half of the estimated eight million handicapped children in the United States were not receiving appropriate services. All categories of handicapping conditions and all age groups were affected. For example, the Office of Education estimated that 29 percent of deaf and 82 percent of hard-of-hearing children were unserved. Figures for other categories of handicapping conditions varied from a low of 17 percent of mentally retarded children to a high of 88 percent of learning-disabled children unserved.

Congress found that this failure to appropriately educate handicapped children harmed both the children and their families and, furthermore, resulted in substantial costs to society. Children were denied "the chance to develop their abilities as individuals and to reach out with their peers for their own personal goals and dreams." Parents' and brothers' and sisters' lives were often

profoundly disrupted by the unending burden of caring for the uneducated handicapped child. Moreover, Congress found equally great costs to society. Children capable of becoming taxpaying members of society instead became permanently dependent on the taxpayers. Thousands of the more severely handicapped were forced into public institutions when their families could no longer care for them. Finally, society lost the benefit of the contribution the children could have made if provided an appropriate education.

Based upon the voluminous record before it, including the advice of special education experts and school officials, Congress enacted P.L. 94-142. The amendments the Reagan Administration now proposes must be understood in the context of the history that precedes them.

HHS FINALIZES RULES EXTENDING SSI AND MEDICAID BENEFITS
FOR CERTAIN SSI RECIPIENTS WHO WORK

On April 9, 1982, the Social Security Administration published final regulations implementing two provisions of P.L. 96-265, the Social Security Disability Amendments of 1980. One provision provides that individuals who lose eligibility for regular Supplemental Security Income (SSI) benefits because they demonstrate the ability to perform substantial gainful activity (SGA) may become eligible for special SSI cash benefits. In essence, this provision eliminates the substantial gainful activity test for SSI beneficiaries.

By law SSI recipients who earn in excess of \$300 a month are considered to be engaging in substantial gainful activity and therefore not disabled. Prior to P.L. 96-265 all such individuals had their SSI benefits abruptly terminated. The April 9 rules make it possible for SSI recipients engaging in SGA to have their SSI benefits continued and reduced gradually as their income rises. SSI benefits will be phased out through a process whereby benefits are reduced one dollar for every two dollars earned.

The second provision implemented by the new rules extends eligibility for Medicaid to certain former SSI recipients.

The purpose of both of these changes is to remove certain disincentives for SSI recipients who want to work but cannot do so without losing the SSI payments and medical support they need. Both provisions are effective for a three year demonstration period beginning January 1, 1981. To date, interim rules published January 22, 1981, have governed the operation of the provisions. At the end of the three years SSA will report to Congress on the effectiveness of the changes in promoting work by SSI disabled and blind recipients.

The special SSI cash benefits are payable through December 1983 so long as the individual continues to have a disabling impairment and to meet all other requirements for SSI eligibility, e.g., the resources test.

If an individual's earnings and other income are great enough to reduce his or her federal SSI benefits to zero, eligibility for special SSI cash benefits ends. However, even if cash benefits are stopped, the individual may still acquire a special eligibility status for purposes of Medicaid. This special eligibility status applies as long as the individual:

1. continues to be blind or have a disabling impairment;
2. except for earnings, continues to meet all the other requirements for SSI eligibility;
3. would be seriously inhibited from continuing to work by the termination of eligibility for Medicaid services; and
4. has earnings that are not sufficient to provide a reasonable equivalent of the benefits (SSI, state supplemental payments and Medicaid) which would be available if he or she did not have those earnings.

DEEMING RULES UNDER SSI ALTERED TO BE
CONSISTENT WITH TREATMENT OF KATIE BECKETT

The Social Security Administration (SSA) has altered the deeming regulations for the Supplemental Security Income (SSI) program to allow certain SSI beneficiaries who, in the past, were eligible for Medicaid if institutionalized but not if living in the community, to retain their Medicaid coverage when living at home or in other community-based facilities.

In most states there is a direct connection between SSI eligibility and Medicaid eligibility and implementation of the SSI deeming rules therefore affects eligibility for Medicaid. As those rules are currently implemented, they result, in some circumstances, in the unnecessary institutionalization of patients with consequent higher costs to state and federal governments.

Unnecessary institutionalization is fostered by the provision in the Social Security Act which applies the deeming rules only to individuals living in the same household as their parents or spouse. Under current regulations, an institutionalized individual is considered not to be living in the same household as the individual's family, and as a result, family income is not deemed to the individual. The institutionalized individual may therefore be eligible for SSI payments (and hence in most states for Medicaid), even in cases where application of the deeming rules would make the individual ineligible if living at home. To retain SSI and Medicaid eligibility, some patients remain institutionalized even though their medical needs could be met at lower costs if they were living at home.

President Reagan drew attention to one such case in November, 1981, involving a child, Katie Beckett, who continued to be hospitalized despite the fact that her medical conditions could be treated at home at substantially less expense. As a disabled individual, the child was eligible for SSI in the hospital, and hence in her state for Medicaid, but she would have lost SSI and Medicaid eligibility had she moved home because her parents' income would have been deemed to her and the income would have exceeded SSI eligibility limits. In light of substantial cost savings that would result to the federal government from the child's living at home, the Secretary of Health and Human Services, Richard Schweiker, determined that it would be inequitable under the circumstances to apply the normal deeming rules in determining her eligibility. She was therefore able to move home, retain her SSI and Medicaid eligibility, and continue to receive medical treatment at a substantial savings to the Medicaid program.

There are many other currently institutionalized persons who also could be satisfactorily treated at home at less cost to the government but who remain institutionalized to avoid losing Medicaid eligibility through operation of the SSI deeming rules.

The new rules contain two approaches to resolving this problem. First, there is an interim approach which involves the establishment of a board within the Department of Health and Human Services (HHS) that will, in appropriate cases, determine whether or not the normal SSI deeming rules should be applied. The facts of each case will be individually examined to determine whether it would be inequitable under the circumstances to consider family income and resources in determining

an individual's eligibility for SSI payments.

The board will apply two basic principles in every case. First, a determination not to apply the SSI deeming rules must prospectively result in savings to the Medicaid program. This requirement would be met, for example, by showing that a currently institutionalized Medicaid recipient who would otherwise remain in the institution could be treated less expensively at home and that Medicaid expenses would therefore be less.

Second, in each case it must be shown to the satisfaction of the board that the quality of medical care provided to the person will be maintained after deinstitutionalization. This question may be of concern particularly in states whose Medicaid programs do not offer extensive medical services for persons living at home. Ordinarily the board would be satisfied by appropriate assurances of the attending physician or institution, subject to requests by the board for further information.

In addition to these two basic requirements, the board may impose additional requirements or standards in particular cases depending on the facts presented.

No specific method of application for a board determination is being prescribed except that all applications must be made on behalf of the individual by a state Medicaid agency, which must recommend that the SSI deeming rules not be applied.

Where the board determines not to apply the usual SSI deeming rules, it will ordinarily do so in a manner that maintains SSI eligibility, but does not result in unnecessary SSI program expenditures. Thus, the board will typically apply the deeming rules to the extent necessary to result in a minimal SSI or federally administered, state optional supplementary payment. That minimal payment would be sufficient to maintain Medicaid eligibility, which is the purpose of the board's action. All determinations by the board would be subject to revision based on new information or changed circumstances. The board would consider only application of the SSI deeming rules. All other aspects of determining SSI eligibility would be handled by the SSA under existing policies and procedures.

The board would also accept applications from states that do not link Medicaid eligibility to the receipt of SSI payments.

The other approach being taken is to allow states to take advantage of the flexibility created under the Medicaid waiver for in-home and community-based services. The Omnibus Budget Reconciliation Act of 1981 provided for a new waiver program to offer a wide array of home and community-based services that an individual may need to avoid institutionalization. The purpose of this legislation was to bring about cost savings and other benefits of deinstitutionalization.

Under the waiver program, a state Medicaid plan may provide approved home and community-based services to individuals who would otherwise require the level of care provided in a skilled nursing facility or intermediate care facility, the cost of which could be reimbursed under the state Medicaid plan. This provision allows a state to provide home and community-based services under its Medicaid plan to individuals who

would be Medicaid-eligible if institutionalized, even if they would be ineligible for Medicaid while living at home because of the SSI deeming rules, or some other reason.

As stated earlier, the policy of individual deeming determinations is being utilized on an interim basis only, pending development by the states of appropriate programs under this new statutory authority allowing waivers for home and community-based services. The regulations provide that the board will continue case-by-case evaluation only through April 30, 1983, unless extended. Determinations made by the board would continue in effect after April 30, 1983, but would be subject to change. It is anticipated that determinations could be terminated for individuals residing in states that have adopted programs of home and community-based services.

SSA TO IMPLEMENT
WORK INCENTIVES UNDER
SSI AND SSDI

With two April Federal Register regulatory announcements, the Social Security Administration (SSA) has begun to implement several work incentive initiatives authorized by P.L. 96-265, the "Social Security Disability Amendments of 1980."

• Medicaid Services and SSI Flexibility

On April 9, SSA issued final regulations to implement sections 201 (a) and (b) of P.L. 96-265 which authorizes a special benefit status and continued Medicaid eligibility for certain severely disabled Supplemental Security Income (SSI) recipients who recently earn over the substantial gainful activity (SGA) level. The Carter Administration had begun the implementation of these provisions and had set-aside \$181 million for its start-up; these efforts were postponed indefinitely by the Reagan Administration but now appear to be back-on-track. Unfortunately, these demonstrations are authorized for 1981, 1982, and 1983; because of bureaucratic delay, the demonstration will run just over a year rather than the originally scheduled three years.

P.L. 96-265 had also extended this eligibility for Title XX Social Services but the Congress, through its P.L. 97-35 Budget Reconciliation Act, no longer requires states to provide social services to SSI recipients and so the P.L. 96-265 provision is moot. This demonstration is targeted to those severely disabled persons who can earn more than SGA (and thus lose SSI eligibility) but who require supportive services in order to retain such employment. Further information is available from Fred Miranda, Legal Assistant, 3-A-3 Operations Building, 6401 Security Boulevard, Baltimore, MD 21235 (301-594-7341.)

• Experiments and Demonstrations

On April 12, 1982, SSA issued proposed regulations to implement Section 505 of P.L. 96-265 which authorizes SSA to conduct experiments and demonstration projects to test alternative conditions and limitations for stimulating work opportunities for both SSI and SSDI (Social Security Disability Insurance) recipients. SSA may waive compliance with benefit requirements, may alter requirements, may alter Medicare benefits and coverage, and may reduce benefits based on earnings. Additionally, SSA may "stimulate new forms of rehabilitation." Information is available from Henry D. Lerner, Legal Assistant, Office of Regulations, SSA, 6401 Security Boulevard, Baltimore, MD 21235 (301-594-7414)

HUD ANNOUNCES FY 1982
SECTION 202 FUND AVAILABILITY:
PURCHASE OF EXISTING HOUSING
FINALLY ALLOWED

The April 20, 1982 Federal Register contains an announcement of fund availability for Section 202 loans to nonprofit organizations for housing for the elderly and disabled. These loans are administered by the Department of Housing and Urban Development (HUD).

- Purchase of Existing Housing

P.L. 96-399, the "Housing and Community Development Act of 1980," authorized the acquisition and moderate rehabilitation of existing housing for the handicapped under the Section 202 program. The FR announcement declares, "Subject to issuance of regulations that are presently being developed, applications may also be accepted for loans for the acquisition with or without moderate rehabilitation of housing and related facilities for use as group homes for the nonelderly handicapped."

- Chronically Mentally Ill Eligible

For several years HUD refused to accept the chronically mentally ill for Section 202 eligibility. The Carter Administration launched a special demonstration program for this population. The April 20 announcement now allows "projects designed exclusively for the chronically mentally ill" to be "eligible under the same conditions and criteria as other projects designed solely for the nonelderly handicapped, except that only group homes for up to 15 persons and independent living complexes to serve up to 20 persons may be proposed..."

- Project Size Criteria

Existing program instructions for the nonelderly handicapped have been modified by the FR announcement to permit group homes to serve up to 15 persons on one site and independent living complexes to include up to 40 units on one site.

- Deadlines and Further Information

The deadline for applications is June 30, 1982. Further information is available from the HUD Field Office. The central office contact, merely for field office location information, is the Office of Multifamily Housing Development, Elderly and Condominium Health Facilities Division, HUD, Room 6136, 451 Seventh Street, S.W., Washington, DC 20410 (202-755-6528).

DISABILITY AMENDMENTS CLEAR HOUSE WAYS AND MEANS

On May 19, 1982, the House Ways and Means Committee approved H.R. 5700, now renumbered H.R. 6181, the Disability Amendments of 1982. Two provisions, Sections 5 and 7, of the bill have been consistently opposed by the ARC and other disability organizations as well as the Save Our Security (SOS) Coalition. (See lead article in April, 1982 Government Report.) Due to this opposition the bill was withdrawn from full Committee consideration on April 28 for further modification. Subsequently, on May 19 the revised bill, now H.R. 6181, was again brought to the full Committee on Ways and Means. At this time the Committee approved the bill and reported it.

The Subcommittee on Social Security's modification to Section 5 of the bill was unsatisfactory to disability organizations, SOS, and to Representative Harold Ford (D-Tenn.) who again offered his amendment to delete that portion of Section 5 which requires closing of the record on evidence at the reconsideration level of appeal for persons whose disability benefits have been terminated. The Committee rejected Representative Ford's amendment by a vote of 14 yeas - 17 nays.

The basic problem with H.R. 6181 is that it does not adequately address the problems which have emerged as a result of the Social Security Administration's massive terminations from the disability rolls of severely and permanently disabled persons who are unable to work. In addition, advocacy groups feel that Sections 5 and 7, if enacted, will aggravate the current problems by creating further delays in the adjudicative process and violating the due process rights of disabled beneficiaries to an impartial hearing before an Administrative Law Judge (ALJ). These opinions were born out in testimony on May 21 before the House Select Committee on Aging. Representative Claude Pepper (D-Fla.), Chairman of the Committee, heard from Social Security beneficiaries, state agency personnel and an Administrative Law Judge regarding the problems created by the Social Security Administration's continuing disability review process. As a result of the hearing Representative Claude Pepper will seek a rule governing consideration of H.R. 6181 on the House floor which will allow amendments to be offered on both Section 5 and Section 7. Currently, the ARC and other disability organizations are communicating their concerns about H.R. 6181 and the need for amending Sections 5 and 7 to all members of the House of Representatives.

The Senate bill also endorses the requirement that tenants pay 30 percent of their income towards their rent and specifies that only those families determined to be very low income (i.e., at or below 50 percent of the area median income) can qualify for assistance under the modified certificate program.

The House bill continues support for the low income assisted housing programs including the Section 8 Rental Assistance program. Assisted housing is authorized at \$15.6 billion which is over a 10 percent decrease from the 1982 authorization levels. However, this commitment to assisted housing represents a sound rejection of the Administration's desire to virtually eliminate the assisted housing programs. H.R. 6296 also would repeal two major provisions of the Omnibus Reconciliation Act adopted last year. The rent increase to 30 percent of income (up from 25 percent) would be repealed as would the limits on the proportion of tenants with incomes between 50 percent and 80 percent of the median income. The bill would also prohibit other rent increases proposed or under consideration by HUD including counting food stamps as income and eliminating or reducing medical expense deductions. It would require exclusion from income of \$400 for each minor, handicapped or elderly person or student, as well as extraordinary medical expenses and child care costs related to working.

The good news is that both H.R. 6296 and S. 2607 retain the HUD Section 202 Direct Loan program for housing for elderly and disabled people. The House bill provides \$843.1 million for Section 202 (up from \$830 million in fiscal year 1982) to finance 16,000 units. The Senate bill authorizes \$790 million for 15,000 units. In addition, S. 2607 makes the following changes to Section 202:

- (1) provides that the interest rate on Section 202 loans be set annually at the rate of the average interest rate on Federal obligations as of the end of the previous fiscal year or at 9 percent, whichever is lower;
- (2) permits any sponsor to voluntarily provide funds from other sources for appropriate amenities if they are not financed or subsidized with federal money;
- (3) directs the Secretary of Housing and Urban Development (HUD) to assure the inclusion of special design features and congregate space necessary to meet the needs of elderly and handicapped people;
- (4) encourages the provision of small and scattered site group homes and independent living facilities for non-elderly handicapped persons and families; and
- (5) provides that a Section 202 sponsor or borrower may select the contractor to be employed in the construction of a Section 202 project on either a negotiated basis or a competitive basis, unless the Secretary disapproves the selection.

The House bill caps the interest rate for Section 202 loans at 9.25 percent. H.R. 6296 also modifies certain requirements for the Section

202 program which were recently proposed in regulation by HUD. First, it would provide that unless otherwise requested by the sponsor, a maximum of 25 percent of the units in a project financed under Section 202 may be efficiency units, subject to a determination by the Secretary that such units are appropriate for the elderly or handicapped population residing in the vicinity of the project or to be served by the project. The intent of this provision is to ensure the financial viability of projects in areas where marketing a higher number of efficiency units would present a difficulty and to clarify that the Secretary shall not impose a requirement that a certain percentage of units in such projects be efficiency units.

The bill would also codify the current practice which requires a minimum capital investment on the part of the sponsor. This investment is designed to ensure the commitment of the nonprofit organization and protect the initial viability of the project. Because the Section 202 direct loan is intended to cover 100 percent of the cost of construction and financing, the minimum capital investment is returned to the sponsor after three years of operation. The House bill would direct the Secretary of HUD to limit such an investment to no more than \$10,000. The House Committee believes that this figure is sufficient to ensure the commitment of the nonprofit sponsor, but not so great as to limit the ability of small nonprofit organizations representing minority, handicapped and rural elderly from participating in the program.

By prohibiting the Secretary from requiring an equity participation by a sponsor, the bill would continue the current practice of providing Section 202 direct loans that cover the entire cost of developing a project. It would also, like the Senate bill, permit sponsors to include suitable amenities and design features which enhance the living environment for residents if the funds for such amenities are provided voluntarily by the sponsor.

Finally, both housing bills would provide for the continuation of the Congregate Housing Services Program. This program provides supportive services to elderly or handicapped residents of public housing and Section 202 financed housing. The House bill provides for a one year authorization for fiscal year 1983 of \$10 million. The Senate bill authorizes \$10 million for fiscal year 1983, and \$11 million and \$12 million for fiscal years 1984 and 1985, respectively.

HHS ANNOUNCES NEW PLAN FOR BOARD AND CARE FACILITIES

The Secretary of the Department of Health and Human Services, Richard S. Schweiker, has announced an eight-point plan "to help improve safety conditions in the nation's estimated 30,000 board and care homes" serving elderly and handicapped persons. The new plan involves expanded assistance to the states which are responsible for overseeing board and care facilities. Specific attention will be focussed on a law passed in 1976, the so-called Keys Amendment, which requires states to establish health and safety standards for residential settings serving a significant number of Supplemental Security Income (SSI) recipients.

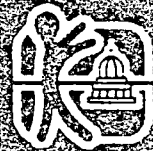
Secretary Schweiker's announcement follows a year-long review of board and care policy and of Keys Amendment implementation. As part of this review process a report on board and care was completed by the HHS Inspector General. Secretary Schweiker's plan implements several of the recommendations contained in this report. The new eight-point plan includes:

- **SANCTIONS**--The new plan will enable HHS to impose sanctions on any state which fails to certify that it maintains and enforces safety and related standards. The amendments to the Older Americans Act require nursing home ombudsmen to investigate complaints in board and care homes. The department will require states to certify compliance with the Keys Amendment as part of each state's Older Americans Act plan. Where problems are apparent, some federal funding provided under the Older Americans Act could be withheld. In the past, the only sanction available to HHS has been to withhold some Supplemental Security Income benefits from SSI recipients who live in unsafe board and care homes, a sanction widely criticized.
- **FIRE SAFETY STANDARDS**--HHS will provide approximately \$400,000 to the National Bureau of Standards this year to complete development of fire safety standards for board and care homes.
- **TECHNICAL ASSISTANCE**--HHS' Office of Human Development Services will establish an information clearinghouse to disseminate data on best current practices as well as research in the board and care area.
- **HHS COORDINATION**--A new management unit will be formed within HHS to focus and coordinate board and care activities throughout the department.
- **MODEL STATE STATUTE**--As suggested by states, a model statute and state program will be developed under HHS contract by a national organization concerned with the board and care field.
- **REPRESENTATIVE PAYEES**--Some SSI payments are sent to custodians, including board and care home proprietors. The proprietors will now be required to show their homes comply with applicable state standards in order to receive SSI payments for the beneficiary.
- **MEDICAID WAIVERS**--Under changes made last year, states may seek waivers from HHS allowing them to use Medicaid funding for home and community based care. The new plan will require that when such funding would go to board and care homes, waivers could be granted only to states which are in compliance with the Keys Amendment.
- **REVIEW**--The Keys Amendment requires states to certify they maintain and enforce standards for board and care homes. This certification will be reviewed by the Administration on Aging, the part of HHS which administers the Older Americans Act.

The Administration on Developmental Disabilities (ADD), within the Office of Human Development Services (OHDS), has been designated by Secretary Schweiker to spearhead the implementation of the new plan. The ARC and other organizations representing mentally retarded and developmentally disabled people are in close contact with ADD and have been assured that the new plan will address and be fully applicable to those board and care facilities serving mentally retarded, developmentally disabled and other handicapped persons.

IMMEDIATE
ATTENTION

DD FUNDODGRAM



12/01/81

NATIONAL ASSOCIATION OF STATE
MENTAL RETARDATION PROGRAM
DIRECTORS, INC.
2001 JEFF DAVIS HWY SUITE 806
ARLINGTON VA 22202

COMMUNITY CARE WAIVERS

ALL CONSUMERS, PROVIDERS, STATE OFFICIALS
AND MR/DD PROFESSIONALS

NOW AVAILABLE--THE FIRST INDEPTH ANALYSIS OF A RECENT CHANGE IN
FEDERAL LAW PERMITTING STATES, UNDER CERTAIN CIRCUMSTANCES, TO
EXPEND MEDICAID DOLLARS ON COMMUNITY-BASED SERVICES TO ELIGIBLE
ELDERLY AND DISABLED PERSONS.

PROVIDES A DETAILED EXPLANATION OF THE PURPOSES AND OPERATION OF
THIS NEW WAIVER PROVISION, AUTHORIZED UNDER THE OMNIBUS BUDGET
RECONCILIATION ACT OF 1981.

Section 2176 of the Omnibus Budget Reconciliation Act of 1981 (P.L. 97-35) added a new provision to Title XIX of the Social Security Act (Section 1915(c)), granting the Secretary of Health and Human Services authority to waive existing statutory requirements in order to permit states to finance non-institutional services for certain elderly and disabled persons through the federal-state Medicaid program. Only Title XIX-eligible recipients, who otherwise would require care in a skilled nursing or intermediate care facility, may qualify for non-institutional, long term care benefits.

The latest issue in NASMRPD's highly-praised series of special reports on federal policy issues offers a comprehensive explanation of the legislative history leading to the enactment of Section 1915(c), as well as a detailed explanation of the statutory and regulatory conditions a state must fulfill to qualify for a waiver. Entitled The Medicaid Home and Community-Based Care Waiver Authority, this fact-filled volume contains:

- a review of the factors which motivated Congress to include the waiver provision in the 1981 legislation;

- an indepth analysis of the assurance a state must provide to qualify for a home and community-based care waiver;
- a deliniation of the types of non-institutional services potentially reimbursable under a state's waiver program, plus a review of the criteria and processes a state must use in determining the eligibility of elderly and disabled persons for such services;
- an elaboration of other features of the waiver process, including federal review, approval and monitoring procedures and the content and format of state waiver requests;
- suggested issues which state officials should consider in drafting a waiver request;
- two hypothetical cases illustrating the numerous factors that state officials must consider in calculating comparative per capita costs of institutional and non-institutional care; and
- copies of the verbatim language of Section 1915(c) and HHS's implementing regulations, issued on October 1, 1981.

In summary, this new publication offers state mental retardation officials, providers of non-institutional services to Medicaid recipients and other interested parties a practical guide to federal policies governing the new home and community-based care waiver authority. Order your copy now!

* * * * *

Those interested in a global overview of the 1981 reconciliation bill's impact on federally-funded services and benefits for developmentally disabled persons should order the two previous issues in the 1981 Federal Funding Inquiry series: Status of the Reagan Budget Proposals (April, 1981) and Congressional Action on the Reagan Budget Proposals (August, 1981). For details on these publications, check the appropriate box below.

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Summary of Medicaid Home and
Community-Based Care Waiver Request

MONTANA

- A. Types of Waivers Requested. Montana requested permission to pay for certain non-institutional services through the Medicaid program, and also asked for approval of waivers of the "statewideness" (Section 1902(a)(1)) and "comparability" (Section 1902(a)(10)) provisions of the Act. The scope of the requested waiver is quite limited, since the planned community-based services are restricted to current residents of two community ICF/MR facilities (Parkside Manor and Westmont Community Center) located in one county. The primary motivation for the request is to finance, through Title XIX, community-based services for 39 of the 48 clients currently residing in one private ICF/MR facility (Parkside Manor), which is scheduled to be closed later this year, thus generating an immediate need to locate alternative placements for such residents. In its waiver request, state officials indicate that they plan to submit a second, more comprehensive waiver request later this year.
- B. Reimbursable Services. The state requested approval to provide the following types of Title XIX reimbursable, non-institutional services under its waiver program for eligible developmentally disabled clients currently being served in the two target ICF/MR facilities.
- Habilitation services. This term is defined as "...intervention which is designed to assist in the development of client skills or the reduction of behavior which interferes with client development." The state intends to deliver this service in "...all alternative living arrangements that serve persons individually or in small groups", as well as in adult day programs. The specific types of habilitative services to be covered under the State's waiver request are:
 1. Residential
 - adult community homes: includes habilitation and training in such areas of daily living skills as self-help skills and home and community life skills, and the provision of supervision to developmentally disabled individuals, 18 years of age and older.
 - children's community homes: includes habilitation and training in such areas of daily living skills as self-help skills and home and community life skills, and the provision of supervision to severely, multiply-handicapped developmentally disabled individuals, ages 5-21 years.

- semi-independent living and training: includes habilitation and training in daily living skills by outreach workers, to assist developmentally disabled individuals, ages 18 years and over, who have achieved designated skills for semi-independent living.

2. Family and children habilitation services

- family focused training: includes training family members so that they can design and implement developmental/behavioral programs, advocate fully and appropriately for the utilization of community services for their child.
- child focused services: includes training family members to conduct specific skill acquisition or behavioral intervention programs with their child.
- client training: includes direct training by family service staff with an individual living in a natural or foster home for the purpose of skill acquisition or behavioral intervention.

3. Adult day services: includes basic life skill training, pre-vocational training, and retirement day skills (leisure skills).
4. Respite care services: short-term services to temporarily relieve a MR/DD client's family or home provider in the case of unforeseen emergencies or of the daily demands and stresses of caring for a handicapped person.
5. Case management services: Is defined as "services whereby an individual or organization is responsible for locating, coordinating, and monitoring services to developmentally disabled individuals."
6. Homemaker services: This service includes "general household activities (meal preparation and routine household care) provided by an individual, either on a temporary basis when the individual regularly responsible for these activities is temporarily absent, or on a regular basis because of the client's inability to perform the tasks for him or herself."
7. Nursing and other professional services: Professional services will be provided as prescribed in the client's approved written plan of care and may include: nursing, physical therapy, occupational therapy, speech therapy, and psychological services.

The State's proposal makes it clear that, in the case of habilitation-residential (provided in adult community home, children's community home and semi-independent living), Medicaid reimbursements under the waiver will exclude all room and board costs (e.g., the provision of shelter and three meals a day to each resident). Only service costs will be reimbursable under the Medicaid waiver.

- C. Health and Welfare Safeguards. In its request, Montana provides assurances that existing operating standards of the Department of Social and Rehabilitation Services, which govern the various elements of services to be provided, will be observed. The existing standards cover the licensure and certification of both programs and professional staff. In addition, as of July 1, 1982, the health, safety and sanitation portions of the standards of the Accreditation Council for Services for Mentally Retarded and other Developmentally Disabled Persons (ACMRDD) will also be applicable. Furthermore, an annual review of service quality and appropriateness will be conducted in conjunction with the Client Program Evaluation staff of the Developmental Disabilities Division.
- D. Financial Accountability. The State will maintain, and require providers to maintain, financial accountability for funds expended on services offered under the waiver. Current accountability requirements imposed on state and contract providers will be continued. These requirements include: the submittal of monthly financial reports, records retention, bookkeeping and financial transactions audit trial and client funds policy. Reasonable, necessary and allowable cost methods will be used to determine reimbursement rates for waived services, as is currently the state's practice with other Medicaid-funded long term care services.
- E. Individual Assessments and Service Eligibility. Level of care determinations have already been made for the population addressed in this waiver request, since they have been residing in an ICF/MR-certified facility and state utilization control procedures have confirmed their need for continued ICF/MR services. However, an evaluation will be completed to ensure that the alternative services offered properly address the individual needs of the target population. This evaluation will be conducted by, or under the supervision of, an interdisciplinary team consisting of a social worker, a physician and at least one Developmental Disabilities Professional Person (as certified by the State of Montana) or a Qualified Mental Retardation Professional (42 CFR 442.401--QMRP). This same interdisciplinary team is responsible for developing an Individual Habilitation Plan within one month of the client's placement. Home and community-based services will only be furnished under a written plan of care which has been approved, in writing, by the Montana Department of Social and Rehabilitation Services.

The Developmental Disabilities Professional Person, or QMRP, is the individual responsible for ensuring that the client's needs are evaluated and that the plan of care adequately addresses his/her needs.

As stated earlier, the eligible population for waived services has been defined as the current developmentally disabled residents of two ICF/MR certified facilities (a total of 55 clients), who have been identified as needing the non-institutional services proposed in the state's waiver request.

- F. Client Choice. The Department of Social and Rehabilitation Services (SRS) has provided assurances that if a resident is determined to be likely to require the level of care offered in a SNF, ICF, or ICF/MR facility, the recipient or his or her representative will be informed of the feasible alternatives, if any, available under the waiver, and will be permitted to choose among them. If there is a finding that home or community-based services are not feasible in a particular case, the applicant and beneficiaries will be offered procedural protections afforded under the Medicaid administrative hearing process, as required in 42 CFR Part 431, Subpart E.
- G. Comparative Per Capita Expenditure Estimates. Estimates of the total population in need of waived services were based on individual evaluations of clients served in the two target ICF/MR facilities and the costs of services in FY 1980. The proposed cost estimates are derived from present costs of similar services and upon preliminary assessments of specific client needs. The figures represent annualized costs with an assumed 8 3/4 percent inflation rate in FY 1983 and FY 1984. The state's calculations on the population currently residing in Parkside Manor are summarized in the following table:

	<u>1981-82</u>	<u>1982-83</u>	<u>1983-84</u>
A	9	9	9
B	\$12,400	\$13,500	\$14,700
C	39	39	39
D	\$15,200	\$16,100	\$16,000
F	48	48	48
G	\$16,300	\$18,000	\$19,700
H	-0-	-0-	-0-
I	-0-	-0-	-0-

Where:

- A = the estimated number of persons who would receive care in SNF, ICF, or ICF/MR facilities if the proposed waiver is approved.
- B = the estimated annual Medicaid payment if the waiver is approved (N.B., the state has assumed an eight and three-quarters (8.75) percent inflationary increase for both FY 1983 and FY 1984).

- C = the estimated number of recipients of waived services.
- D = the estimated annual cost for clients receiving home and community-based services under the waiver. (N.B., these estimates are based upon present costs of similar services, assuming an 8.75 percent inflationary increase in both FY 1983 and FY 1984.
- F = the estimated number of persons who would receive care in SNF, ICF, or ICF/MR facilities in the absence of a waiver (numbers reflect 47 persons for ICF/MR level of care, and one person for ICF-general level of care.)
- G = the estimated annual Medicaid payment per institutional resident in the absence of a waiver. (N.B., assuming an 8.75 percent inflation rate in FY 1983 and FY 1984.)
- H = the estimated number of MR/DD beneficiaries who will be eligible for Medicaid-reimbursable home and community-based services in the absence of a waiver.
- I = the average per client cost of services provided under H.

Applying these utilization and cost estimates to the mathematical formula contained in Section 441.303(d) of HHS regulations, Montana officials concluded that the average per client expenditures for the provision of services under the waiver will not exceed the costs of services without the waiver:

<u>FY 1981-82</u>		<u>FY 1981-82</u>
Expenditures Under the Waiver		Expenditures Without the Waiver
$\frac{(9 \times \$12,400) + (39 \times \$15,200)}{48}$	≤	$\frac{(47 \times \$16,500) + (0) + (1 \times \$6,300)}{47}$
\$14,700	≤	\$16,300

Similar calculations are included for FY 1982-83 and FY 1983-84. In an addendum to its waiver request, Montana officials provided similar calculations for a 7-bed, ICF/MR facility (Westmont Community Center) which is also located in Lewis and Clark County. These figures are not included here because the state's request assumed no change in the status of such residents over the three year period.

- H. Annual Impact Report. The Montana Department of Social and Rehabilitation Services will annually provide HHS/HCFR with information regarding the impact of the waiver on the type, amount, and cost of services provided under the State's Medicaid Plan and the waiver, and on the health and welfare of the recipients. This information will be consistent with a data collection plan to be promulgated by HCFR.

Summary of Medicaid Home and
Community-Based Care Waiver Request

LOUISIANA

- A. Types of Waivers Requested. In addition to permission to pay for certain non-institutional services through its Medicaid program, Louisiana asked for waivers of the "statewideness" (Section 1902(a)(1)) and "comparability" (Section 1902(a)(10)) provisions of the Act, in relationship to one of its three non-institutional services to be provided under the waiver. "Adult Day Health Services" (defined below) would be limited to four specified parishes "where centers are currently operating," and to eligible individuals age 18 and older. Other services will be made available on a statewide basis.
- B. Reimbursable Services. Louisiana requested approval to provide the following types of Title XIX-eligible services under its waiver program:
- Adult Day Health Services for eligible physically or mentally-impaired clients who require day care services because they cannot remain at home alone during the day. The primary target population will be frail elderly and other non-developmentally disabled individuals. Services will be provided in a licensed day care facility, based on the client's: (a) inability to prepare meals; (b) need for supervision to keep him/her from potential danger; (c) hearing and/or sight problems; or (d) other physical, mental or emotional problems. Two snacks and a meal will be provided as part of the client's program, as well as transportation.
 - Homemaker Services for eligible disabled persons needing in-home and direct personal care. Services will include: (a) general household activities, including meal preparation; (b) assisting the client in bathing, toileting, grooming, eating and ambulating; (c) general supervision, including administering medication and arranging for health care services; (d) providing companionship, emotional support, and social stimulation; and (e) arranging for transportation, completing forms, and acting as an interpreter. Case Management is also covered as part of "Homemaker Services," including: assessment of need, arrangement for utilization of services, referrals and follow-up.
 - Habilitation Services Program (Day Developmental Training Program) provides six hours of daily programming for eligible mentally retarded clients to assist such individuals in:

- developing social and personal skills which are generally acceptable by the public and in a controlled work environment;
- receiving the habilitation necessary for daily living and successful participation in a structured work program; and
- accessing extended remunerative employment in a controlled environment for individuals whose handicapping conditions are a continuing barrier to competitive employment.

An estimated 1,438 mentally retarded clients would be eligible for habilitation (day developmental training) services financed under the waiver during FY 1983.

- C. Health and Welfare Safeguards. In its request, Louisiana provided assurances that Adult Day Health Services and Habilitation Services will be available only through providers licensed by the Division of Licensing and Certification in the State Department of Health and Human Services. Standards for licensure, which were appended to the State's waiver request, cover: (a) for Adult Day Health Services: staff-to-client ratios; qualifications of personnel; care of participants, including nutrition, daily programming, and the physical environment; and general requirements relating to safety and accessibility; and (b) for habilitation services (Day Developmental Centers): client advocacy; program guidelines; individual program plan guidelines; other support services; operational practices; and accountability. Homemaker services will be available from providers "who have the ability to follow oral and written instructions, ability to learn from in-service training and supervision, who have good physical health, including evidence of absence of communicable disease, neatness and cleanliness, means of personal transportation, and experience in household management." Compliance with these standards will be assured by the Department's Office of Family Security (OFS), the State's Medicaid Assistance Unit.
- D. Financial Accountability. The State will maintain, and require providers to maintain accountability for funds expended under the waiver. All Medicaid providers are required to sign a provider enrollment form prior to participating in the program. This provider agreement stipulates that such records as are necessary must be maintained. A similar statement is also on the claim form which must be signed and submitted to bill for Medicaid services. All providers of waived services will be required to submit annual cost reports which will be subject to audit for purposes of assuring financial accountability for funds expended. OFS will make appropriate financial records available to DHHS upon request.

- E. Individual Assessments and Service Eligibility. Louisiana proposes to provide services under the waiver only to individuals who, but for these services, would require the level of care provided in an intermediate care or skilled nursing facility, as defined in federal regulations. Objective evaluations of each client's need for ICF/SNF level of care will be conducted by using the state's existing Title XIX medical and social assessment forms. Medical evaluations will be completed by a licensed physician, and social information will be provided by the individual or agency arranging for the service. In addition, psychological evaluations, by licensed psychologists, will be secured, when appropriate. Reevaluations will be completed periodically. Written documentation of the client assessments will be maintained by the regional offices of the Office of Family Security.

Each service under the waiver will be provided according to an individual plan of care prepared by a team consisting of appropriate disciplines, such as a physician, nurse, social worker, speech therapist occupational therapist, etc., and approved by the Office of Family Security. Each team member will be licensed according to state law. The individual plan of care will be approved by a State Review Team, consisting of a licensed physician, a nurse and a social worker.

Louisiana plans to deny home and community-based care services under the waiver to otherwise eligible clients when the cost of such services can reasonably be expected to exceed the cost of their care in a SNF or ICF.

- F. Client Choice. Applicants for long term care services will be advised of feasible service alternatives at the time of application, unless there is a reasonable expectation that services provided under the waiver would cost more than care in a SNF or ICF. Residents of long term care facilities will be advised of the choice at time of review. Provisions for a fair hearing will be available through existing Medicaid procedures.

- G. Comparative Per Capita Expenditure Estimates. Louisiana's calculations combine figures for SNF, ICF/MR, and two levels of ICF-general care. Estimates for each year 1982, 1983, and 1984 include factors of: (a) a utilization increase of three percent; and (b) an inflation rate of 10 percent, per year, based on the recent history of the State's Medicaid program. The State's calculations are summarized in the following table:

	1982	1983	1984
A	\$25,476	\$25,489	\$25,224
B	11,181	12,030	13,052
C	11,692	12,043	12,404
D	861	947	1,041
F	30,000	30,900	31,827
G	11,181	12,030	13,052
H	2,090	2,152	2,217
I	673	719	769

Where:

- A = Estimated number of beneficiaries who would receive the level of care provided in an SNF, ICF/MR or ICF-level I and ICF-level II (projected SNF-ICF/ICF-MR population minus estimated number who would be deinstitutionalized).
- B = Estimated Medicaid payment per eligible user of such care. (Current appropriation of \$286,865,287 divided by current population in SNF/ICF care, including ICF/MR, inflated by 10 percent annually).
- C = Estimated number of beneficiaries who would receive home and community-based services under waiver or other non-institutional services included under the State Medicaid plan. (Current population receiving services under Title XX or Home Health Services who appear to need SNF or ICF care plus persons to be deinstitutionalized.)
- D = Estimated Medicaid payment per eligible Medicaid user of such home and community-based services or home health services. (Estimated aggregate expenditures under Title XX and Home Health divided by persons receiving these services).
- F = Estimated number of beneficiaries who would likely receive the level of care provided in a SNF, ICF or ICF/MR in the absence of a waiver. (Current SNF/ICF and ICF/MR population plus population currently being served under alternative funding who would be institutionalized in absence of waiver; does not include those being served under Title XIX Home Health Program).
- G = Estimated Medicaid payment per eligible Medicaid user of such institutional care. (Current appropriation of \$286,865,287 divided by current population in SNF/ICF care, including ICF/MR, inflated by 10 percent annually).
- H = Estimated number of beneficiaries who would receive any of the non-institutional long term care services otherwise provided under the State Plan as an alternative to institutional care. (Home health recipients)
- I = Estimated Medicaid Payment per eligible Medicaid user of the non-institutional services referred to in H.

Applying these utilization and cost estimates to the mathematical formula contained in Section 441.303(d) of HHS regulations, Louisiana officials concluded that average per client expenditures for the provision of services under the waiver will not exceed the cost of services without the waiver:

1982
Expenditures Under the Waiver

1982
Expenditures Without the Waiver

$$\frac{(A \times B) + (C \times D)}{(F + H)}$$

$$\frac{(F \times G) + (H \times I)}{(F + H)}$$

\$294,913,968
32,090

\$336,836,570
32,090

\$9,190

\$10,496

Similar calculations are included for FY 1983 and FY 1984.

One critical feature of Louisiana's waiver proposal is the projected dampening effect of waived services on future demand for care in Medicaid-certified institutions. Without the waiver, the number of residents in SNF, ICF and ICF/MR facilities was expected to increase to 30,000 in FY 1982, 30,900 in FY 1983 and 31,827 in FY 1984. These estimates included the 25,656 persons currently residing in such Title XIX-certified facilities, plus an additional 4,344 (in FY 1982) whose care is presently being financed through non-Medicaid dollars but who would require institutional care in a SNF, ICF or ICF/MR facility in the absence of a waiver.

By contrast, state officials estimate that the total number of SNF, ICF and ICF/MR residents can be held to 25,476 in FY 1982, 24,489 in FY 1983 and 25,224 in FY 1984 under the approved waiver. Built into these estimates is the assumption that 180 persons will be deinstitutionalized in FY 1982, 1,947 in FY 1983 and 2,005 in FY 1984, while the demand for future institutional placement increases at three percent per year. The number of eligible residents in ICF/MR-certified institutions is expected to increase only slightly over the three year period of the waiver (from 4,023 in FY 1982 to 4,268 in FY 1984).

H. Annual Impact Reports. On an annual basis, Louisiana will furnish HHS information concerning the types and amount of medical assistance provided and on the health and welfare of the beneficiaries. This information will be consistent with a data collection plan to be promulgated by HHS.

I. Financial Eligibility. In addition to all recipients of SSI benefits (who, by federal law, must be covered under a state's Medicaid program), Louisiana plans to offer waived services to: (1) all individuals otherwise eligible for Medicaid under the state plan; and (2) individuals who are otherwise categorically eligible for SSI and have incomes no greater than 300 percent of the SSI benefit level. Individual's who qualify under the higher income levels will be required to share in the cost of waived services. They will be allowed, however, to retain a reasonable amount for their own subsistence and for the needs of any dependents.

Prepared by:
National Association of State Mental
Retardation Program Directors, Inc.

March 17, 1982

Summary of Medicaid Home
and Community-Based Waiver Request

FLORIDA

A. Types of Waivers Requested. The Florida Department of Health and Rehabilitative Services (DHRS) requested permission to pay for certain non-institutional services through the Medicaid program, and also asked for approval to waive the "statewideness" (Section 1902(a)(c)) and "comparability" (Section 1902(a)(c)) provisions of the Social Security Act. In addition, Florida requested permission to waive two other provisions of the Act:

- Free Choice of Providers (Section 1902(a)(23)): The State requested permission for DHRS case managers "...to specify through the individual care plan the specific provider, type of service, and frequency of services" to be delivered to waiver-eligible clients.
- Financial Eligibility (Section 1902(a)(17)): The State requested approval to serve, under its waiver program, individuals applying for nursing home care in accordance with the State's Institutional Care Program. This, in effect, would waive the deeming of parental income for mentally retarded/developmentally disabled children, who live at home and are SSI eligible due to the level of their disability, but who are not eligible for SSI or Medicaid by virtue of their parents' income level. DHRS has been notified by the Health Care Financing Administration (HCFA) that federal officials intend to deal separately with this section of the State's waiver request.

B. Reimbursable Services. The Florida waiver request included services designed to be generally applicable to infirm elderly, physically disabled, and developmentally disabled individuals as well as services that were designed for specific populations.

The services requested for all financially and otherwise eligible elderly and disabled persons in the state include:

- Case Management: This service is defined as a "...method for the identification of individual client's needs, development of immediate and long term goals, counseling in developing a plan of care and arrangement and monitoring of services through multiple resources for as long as necessary to meet established goals, for the individual."
- Respite Care: This term is defined as "...a demand-response service to provide supervision, companionship, and/or personal care to a physically disabled person, an infirm elderly person, or a developmentally disabled person for a specified period of time." It allows the primary care giver a "...leave

of absence in order to reduce stress, as well as meet a sudden family crisis or emergency."

In addition to the above-listed common service definitions, the State identified four services which provide options to institutional care for developmentally disabled persons. They include:

- Developmental Training: This service "...consists of training in self-care, social, communication, motor, basic knowledge, recreation, daily living, and human growth and development skills. In addition to this comprehensive habilitation programming, social services, health care, food service (less than three meals per day), escort, and counseling services may be included as required by the individual." Both children and adults are eligible to receive such primary support services when they are residing in the community.
- Diagnosis and Evaluation: This service involves "...assessments provided by the D&E Team and/or purchased from professionals." In order to determine the level of care needed, the following D&E assessments are obtained: "psychological, psycho-social, medical, dental, nursing, physical therapy, occupational therapy, recreational therapy, therapeutic visits, basic academic, self-care, daily living, human growth and development, communication, social, motor, and informed consent skills."
- Family Placement: This term refers to "...a range of services available to the developmentally disabled who live at home." Such services are "...directed at maintaining the individual in a home setting, and avoiding placement into an institutional setting." All services to be provided must be identified and authorized in the client's Habilitation Plan.
- Training and Therapies: This service "...includes specialized training in the areas of self-care, vocational, social and motor skills, occupational, physical, speech, recreation therapies and daily living as they complement developmental training services."

C. Health and Welfare Safeguards. Florida officials state in their request that "...all providers of the services requested under the waiver will be authorized as Medicaid service providers and must comply with any applicable State and/or Federal licensing standards, policies, and procedures. Provision and operating procedures of the Department explicitly ensure that the health and safety of recipients will be safeguarded." The pertinent regulations and forms were appended to the waiver requests. All service programs will be monitored by an on-site visit which must occur at least annually. Monitoring will be done at both the state and district office level, the request indicates.

- D. Financial Accountability. Funds expended on home and community-based services under the waiver will be closely monitored by means of a clearly defined audit trail which is applicable to both State and Federal funds. Furthermore, all Medicaid providers must maintain records which fully account for the extent of services provided to eligible recipients and these records will be accessible to appropriate State and Federal officials. The recipient, provider, and paid claims histories are available through the Florida Medicaid Management Information System (FMMIS).
- E. Individual Assessments and Eligibility. Only those beneficiaries who are determined at risk of institutionalization, based on meeting the State's level of care criteria for skilled, intermediate, or intermediate care facility services for the mentally retarded, shall be offered the choice of utilizing the alternate community-based services provided under the waiver program. In addition, in order to receive home and community-based services as an alternative to ICF/MR services, the person must also be developmentally disabled (either retarded, autistic, epileptic, cerebral palsied or otherwise developmentally disabled in accordance with P.L. 95-602) and in need of services provided by the State's Developmental Services Program. A child under five years of age who is a developmental risk, and in need of developmental services is also eligible.

Each person who applies for waiver-financed services must go through a three-step process. The first step, or intake process, involves DHRS social worker obtaining all necessary background information, as well as relevant releases. Next, the applicant is diagnosed and evaluated, which includes eligibility determination. The D&E team is comprised of a coordinator, a clinical social worker, an academic consultant, a psychologist, and a nursing specialist. All assessments are computed within 60 days of the receipt of the referral from the social worker. Lastly, the habilitation plan is developed by the Habilitation Planning Committee, whose membership includes representatives of the D&E team, as well as the client and his/her parent/guardian, Developmental Services social worker, other medical, social, or psychological professionals, and other resource persons, as needed.

A Developmental Services social worker reviews each individual's case semi-annually, with reassessment occurring annually. However, the habilitation plan may be amended at any time the individual's service needs change.

- F. Client Choice. As part of the Habilitation Planning Committee, the client/guardian must concur with all the services, including their amount, duration and scope, and, by signing the developed plan, give authorization for the client to participate in such services. Thus, prior to implementing a habilitation plan for community-based or ICF/MR services, the individual/guardian has participated actively in the choice of services, and decided whether to accept institutional or home and community-based care services.

- G. Comparative Per Capita Expenditure Estimates. Florida offers three levels of ICF/MR longterm care: Sunland ICF/MR (state institutions); ICF/MR Community Facilities; and the ICF/MR Cluster Facilities. The average unit cost of these three levels of ICF/MR care were used to calculate the cost impact of the proposed waiver services. The waiver request included individual cost calculation formulae for each of the levels, as well as a composite for all facilities.

For the purposes of this summary, we have elected to present the summary of the composite formulae:

	<u>1981-82</u>	<u>1982-83</u>	<u>1983-84</u>	<u>1984-85</u>
A	2,470	2,981	3,300	3,310
B	\$1,834.33	\$2,332.75	\$2,520.83	\$2,683.58
C	3,281	3,414	3,560	3,702
D	\$316.38	\$317.76	\$421.72	\$421.72
F	5,571	6,395	6,860	7,012
G	\$1,834.33	\$2,332.75	\$2,520.83	\$2,683.58
H	-0-	-0-	-0-	-0-
I	-0-	-0-	-0-	-0-

Where:

- A = the estimated number of persons who would receive care in Sunland ICF/MR; Community ICF/MR and Cluster ICF/MR facilities if the waiver proposal is approved.
- B = the average monthly cost of all Sunland, Community, and Cluster ICF/MR facility residents if the waiver is approved. (N.B., the state has assumed a 9.1 percent inflationary cost increase in both FY 1984 and FY 1985. costs).
- C = the estimated number of recipients of waived services.
- D = the estimated cost for clients receiving home and community-based services under the waiver. (N.B., this estimate is based on utilization and cost information for the current users of long term care services under consideration, assuming a 9.1 percent inflationary increase in both FY 1984 and FY 1985.)
- F = the estimated number of persons who would receive care in Sunland, Community, or Cluster ICF/MR facilities in the absence of a waiver.
- G = the average monthly cost of a Sunland, Community, or Cluster ICF/MR residents in the absence of a waiver (N.B., assuming a 9.1 percent inflationary increase in both FY 1984 and FY 1985).

H = the estimated number of MR/DD beneficiaries who will be eligible for Medicaid-reimbursable home and community-based services in the absence of a waiver.

I = the average monthly per client cost of services provided under H.

Applying these utilization and cost estimates to the mathematical formula contained in Section 441.303(d) of HHS regulations, Florida officials conclude that the average per client expenditures for the provision of services under the waiver will not exceed the cost of services without the waiver:

<u>FY 1981-82</u> Expenditures Under the Waiver	<u>FY 1981-82</u> Expenditures Without the waiver
$\frac{(2470 \times \$1834.33) + (3281 \times \$316.38)}{(5751 + 0)} \leq \frac{(5751 \times 1834.33) + (0 \times 0)}{(5751 + 0)}$	$\frac{(5751 \times 1834.33) + (0 \times 0)}{(5751 + 0)}$
$\$968.33 \leq \1834.33	

Similar calculations were also included for FY 1982-83, FY 1983-84, and FY 1984-85. It should be noted that while the above calculations reflect a composite of the Sunland, Community and Cluster ICF/MR facilities, separate calculations using the formulae, were included in the request. The projected populations for these programs (under the waiver) are as follows:

Population Projections

	<u>FY 1981-82</u> <u>(9/82-6/82)</u>	<u>FY 1982-83</u>	<u>FY 1983-84</u>	<u>FY 1984-85</u>
Sunland ICF/MR	*1295	*1295	*1295	*1295
Cluster ICF/MR	80	528	648	648
Community ICF/MR	1095	1158	1357	1367

*The Sunland ICF/MR population remains constant in the population projections, because future ICF/MR growth will be restricted to Community ICF/MR and cluster facilities.

The following table shows the number of mentally retarded/developmentally disabled persons Florida anticipates being eligible for services during each year of its waiver program:

	FY 81-82 (4/82- 6/82)	FY 82-83	FY 83-84	FY 84-85 (7/84- 3/85)
Case Management (Casework & D&E)	3,281	3,414	3,560	3,702
Transportation	2,057	2,140	2,232	2,321
Respite	161	168	175	182
Family Placement	44	45	47	49
Training and Therapy	2,016	2,098	2,188	2,275
Developmental Training	1,959	2,039	2,126	2,211

- H. Annual Impact Report. The Department of Health and Rehabilitative Services will provide the Secretary of HHS with an annual report describing the types, amount, and costs of home and community-based services provided under the waiver. This information will be consistent with the data collection plan to be promulgated by HHS.
- I. Financial Eligibility. In addition to all recipients of SSI (who by Federal law must be covered under a state's Medicaid program) Florida plans to set income eligibility units, for individuals participating in home and community-based services, up to 300% of the SSI federal benefit level. Furthermore, they requested that Section 1902(a)(17) of the Act be waived for otherwise eligible individuals residing in their natural homes and participating in the Institutional Care Program (see discussion under A above).
- J. Organizational Responsibility. The Department of Health and Rehabilitative Services is the single state Medicaid agency and, therefore, is the agency responsible for administering the Medicaid waiver program. The Deputy Assistant Secretary for Medicaid, DHRS, will assure that necessary safeguards, including health and safety, adequate and appropriate provider qualifications, and sufficient procedures for financial accountability, are met by the provider. Additionally, staff from the Developmental Services Program Office within the Department will be involved in assuring that services made available to developmentally disabled persons meet minimum quality standards.

Summary of Medicaid Home
and Community-Based Waiver Request

Oregon

- A. Types of Waivers Requested. In addition to permission to pay for certain non-institutional services through its Medicaid program, the State asked for waivers of the "statewideness" (Section 1902(a)(1)) and "comparability" (Section 1902(a)(10)) provisions of the Act, since "...availability of these services is not now uniform in all areas of the state."
- B. Reimbursable Services. Oregon requested approval to provide the following types of Title XIX-reimbursable services under its waiver program:
- For eligible elderly/disabled recipients: housekeeper/chore services; homemaker services; non-medical transportation; services in residential care facilities; services in foster care; and minor physical adaptations to the home.
 - For eligible mentally and emotionally disturbed clients: services in residential care facilities.
 - For eligible mentally retarded and other developmentally disabled clients: case management; services in residential care facilities; services in satellite apartments; activity center services; parent training; respite care; and minor physical adaptations to the home.

Within the State's proposal, non-institutional services for which MR/DD clients will be eligible are defined as follows:

- Case management (2181)*: A service "...responsible for the location, coordination and monitoring of social, habilitative, medical and other services, both formal and informal, to meet the needs of mentally retarded persons and their families.

* The figure in parenthesis includes the estimate number of clients who will be eligible for Medicaid reimbursement under the proposed waiver. These figures do not include the 300 current ICF/MR residents who will be deinstitutionalized during FY 1981-82. Cost estimates for the latter group were derived by applying the weighed average cost of home and community-based services to current program participants.

- Habilitation services (2181): This term generally includes "...a variety of social services provided in day and residential settings designed to maximize the functioning of mentally retarded persons or persons with related conditions." More specifically, the State plans to cover, under its waiver program, the following types of habilitative services:
 - *residential training (391)*: includes monitoring of health care needs, behavior management, money management, social, personal care and practical living skills.
 - *residential care (173)*: includes monitoring of health and personal care needs and maintaining resident's skills/behaviors in order to permit continued community living.
 - *satellite apartment living (214)*: includes rendering necessary assistance and support in the areas of social, personal care and practical living skills which enable the client to live semi-independently in the community.
 - *activity center (410)*: includes supportive and habilitative services in critical independent living, social, recreational/leisure time and work-related skills to enable clients to live in the community.
 - *parent training (678)*: includes in-home services to eligible MR/DD children and their parents to facilitate the acquisition of language and communication, motor, social, and self-help skills.
 - *respite care (315)*: short-term services to temporarily relieve a MR/DD client's family or home provider in the case of unforeseen emergencies or of the daily stresses and demands of caring for a handicapped person.
- Other Services: Minor physical adaptations to a recipient's home also are covered when such modifications are considered "...imperative to enabling persons to remain in or return to the community..." (e.g., grab bars in bathrooms, wheelchair ramps, installing smoke alarms, removing physical hazards, etc.)

The State's proposal makes it clear that, in the case of residential training, residential care and respite care services, Medicaid reimbursements under the waiver will exclude all room and board costs (i.e., the provision of shelter and three meals a day to each resident). Only service costs will be paid for through Medicaid.

- C. Health and Welfare Safeguards. In its request, Oregon provides assurances that existing operating standards of the Mental Health Division, which govern the various elements of service to be provided under the waiver, will be observed. These standards, copies of which are appended to the State's waiver request, cover: the statutory authority, service definitions, case or administrative management procedures, licensure, and renewal requirements, supportive and professional services, admission and release criteria, building and record requirements, resident rights and furnishings, food and health services, safety, sanitation, and procedures for granting exceptions and variances, as appropriate. Biennial, on-site evaluations of each licensed program are conducted by personnel from the State Mental Health Division. In addition, service programs are monitored on an ongoing basis by the community mental health program and the case manager of each individual client.
- D. Financial Accountability. For waiver services to MR/DD clients, the Mental Health Division (MHD) will be responsible for documenting the cost of services and maintaining financial accountability. MHD contractors and subcontractors will be required to complete a quarterly allotment and expenditure report, detailing actual expenditure of state (DMH) funds. In addition, monthly, computerized reports on the number of recipients served, additions, terminations and reasons for such terminations must be submitted to MHD, in accordance with the provisions of the annual contract between the Division and the provider agency. Finally MHD personnel will conduct financial audits of provider agencies, both on a random basis and upon request.
- E. Individual Assessments and Service Eligibility. The Oregon Mental Health Division is responsible for evaluating whether potential MR/DD clients need home or community-based services and if they are likely to require care in an ICF/MR-certified setting in the absence of such home or community-based services. The Division plans to carry out this function through its Diagnosis and Evaluation Services (D&ES), a unit established several years ago to assure that only persons who qualify for ICF/MR services are admitted to such facilities. The process will involve an individualized assessment by an interdisciplinary team, consulting of a physician, a nurse, a psychologist and a social worker. Each member of the team must meet minimum educational and/or experience requirements.

The Community Mental Health Program case manager is responsible for assessing the availability of community resources to meet the identified needs of each client. In addition, in areas of the state where no D&ES team exists, case managers, with special training and experience, will conduct the pre-placement assessment. All case managers must be Qualified Mental Retardation Professionals, in accordance with the specifications of 42 CFR 442.401.

The D&ES team will screen all persons referred for ICF/MR placement and participate in the development of plans of care for individuals admitted to such facilities. The Client Evaluation Record, a computerized assessment tool used with recipients of residential care, residential training, satellite apartment and activity center services, and the Parent Training Evaluation Record, a behavioral checklist used in assessing early child development, will be employed by D&ES teams to document the client's service needs and to develop individual plans of care.

In order to qualify for services paid for under the State's Section 1915(c) waiver program, a client must be found to be mentally retarded and in need of care, treatment or training normally provided in an ICF/MR-certified facility. In determining whether the client needs ICF/MR-type services, the assessment team must document that the individual cannot be maintained in the community (including his/her own home) without services comparable to those offered by an ICF/MR, as defined in applicable federal regulations.

Oregon has not elected to exclude specified groups of otherwise-eligible recipients from waived services on the grounds that the anticipated cost of such services would exceed the cost of care in a SNF, ICF or ICF/MR facility. However, State officials plan to monitor the cost of waived services carefully during the first year of the program and reserve the right, at a later date, to limit services to clients for whom the cost effectiveness of home and community-based services can be established.

- F. Client Choice. During the assessment and eligibility determination process, clients who are eligible for waived services will be informed of the feasible long-term care service alternatives and given a choice regarding the type of service they wish to receive. This choice, which in the case of MR/DD clients usually will be offered by the client's case manager, will include both an institutional option and feasible home and community-based services.
- G. Comparative Per Capita Expenditure Estimates. Estimates of the total population likely to receive waived services were derived, based on agency studies of the characteristics of clients currently receiving service in institutions, nursing homes and community settings. Then, separate weighed average Medicaid expenditures per case were calculated for client's served through the Adult and Family Services/Senior Services Division and the Mental Health Division. Finally, the cost effectiveness of planned services were developed separately for clients who need institutional placement in ICF, SNF or ICF/MR facilities, respectively.

The State's ICF/MR calculations are summarized in the following table:

	1981-82	1982-83	1983-84
A	<u>1,672</u>	<u>1,672</u>	<u>1,672</u>
B	1,821.33	1,985.25	2,144.17
C	2,481	2,481	2,481
D	197.39	215.16	232.37
F	1,972	1,972	1,972
G	1,821.33	1,985.25	2,144.17
H	-0-	-0-	-0-
I	-0-	-0-	-0-

Where:

- A = the average monthly census of residents in ICF/MR-certified facilities *if the proposed waiver is approved.*
- B = the average monthly cost of care for an ICF/MR resident *if the waiver is approved.* (N.B., the State has assumed a nine (9) percent inflationary increase in FY 1982-83 and an eight (8) percent increase in FY 1983-84 costs.)
- C = the estimated average monthly number of recipients of waived services. (N.B., This figure includes 300 MR/DD clients removed from ICF/MR facilities, plus an additional 2,181 who would qualify for ICF/MR admission but can be served more effectively and at less cost through home and community-based services.)
- D = the average monthly cost for clients receiving home and community-based services *under the waiver.* (N.B., These calculations were derived by listing the budgeted costs for each identified element of reimbursable services (see B above), deriving a weighed average cost per case and adding a nine (9) percent inflationary increase in FY 1982-83 and an eight (8) percent increase in FY 1983-84.)
- F = the average monthly census of residents in ICF/MR-certified facilities *in the absence of a waiver.*
- G = the average monthly cost of care for an ICF/MR resident *in the absence of a waiver.* (N.B., Assuming nine (9) percent inflation in FY 1982-83 and eight (8) percent in FY 1983-84.)
- H = the number of MR/DD beneficiaries who will be eligible for *Medicaid-reimbursable home and community-based services in the absence of a waiver.*
- I = the average per client cost of services provided under H.

Applying these utilization and cost estimates to the mathematical formula contained in Section 441.303(d) of HHS regulations, Oregon officials conclude that average per client expenditures for the provision of services under the waiver will not exceed the cost of services without the waiver:

<u>FY 1981-82</u> <u>Expenditures Under</u> <u>the Waiver</u>		<u>FY 1981-82</u> <u>Expenditures Without</u> <u>the Waiver</u>
$(1672 \times \$1821.33) + (2481 \times \$197.39)$	$<$	$(1972 \times \$1821.33) + (0)$
1972		1972
$\$1,792.59 \leq 1,821.33$		

Similar calculations also are included for FY 1982-83 and FY 1983-84. Services for elderly and other disabled persons who qualify for ICF and SNF level of care are calculated separately. Utilization and cost estimates for non-institutional residential care services for emotionally disturbed individuals are built into the ICF calculations.

The key to the Oregon's waiver proposal is the State's plan to deinstitutionalize 300 current ICF/MR residents during FY 1981-82. In effect, the cost savings associated with this step, state officials calculate, will permit the Mental Health Division to extend Medicaid coverage to a total of 2,481 clients in home and community-based services.

- H. Annual Impact Reports. On an annual basis, Oregon's Medical Assistance Unit will furnish HHS information concerning the types and amount of medical assistance provided and on the health and welfare of the beneficiaries. This information will be consistent with a data collection plan to be promulgated by HHS.
- I. Financial Eligibility. In addition to all recipients of SSI benefits (who, by federal law, must be covered under a state's Medicaid program) Oregon plans to offer waived services to three additional groups of recipients. First, in accordance with 42 CFR 435.232, the State intends to provide coverage to aged, blind and disabled individuals who:
- because of their income are not eligible for SSI or Oregon's supplement to SSI;
 - have income below 300 percent of the SSI payment standard;

- would be eligible for Medicaid if institutionalized; and
- will receive home and community-based services.

Second, adults who receive benefits under Oregon's Supplemental Income Payment program will be covered, in accordance with 42 CFR 435.230. And, finally, coverage will be extended to AFDC-eligible children and their families, as specified in 42 CFR 435.711 and 42 CFR 435.712.

The State plans to reduce Medicaid payment for home and community-based services under its waiver program to the extent that any eligible recipient has income and resources which exceed the income disregards outlined in 42 CFR 435.726. In such cases, the recipient will be expected to make up the difference between the state's payment and the actual cost of such services.

J. Organizational Responsibility. In Oregon the Department of Human Resources is the single state Medicaid agency. Responsibility for Title XIX services under the State Medicaid Plan has been delegated to the Medical Assistance Unit of the Department's Adult and Family Services Division. Several other divisions of the Department, however, also are involved in delivering Title XIX services to Medicaid eligible beneficiaries.

In 1979, the Oregon Legislature transferred responsibility for providing Title XIX services to mentally retarded/developmentally disabled and mentally/emotionally disturbed clients to the Department's Mental Health Division. MHD has entered into an agreement with the Adult and Family Services Division, under which MHD assumes responsibility for the following Medicaid functions:

- (a) writing administrative rules governing Title XIX services to clients over age 65 in institutions for mental diseases, inpatient psychiatric services to psychiatric patients, intermediate care facilities services for MR/DD clients, Title XIX outpatient services to eligible MR/DD and M/ED clients and Title XIX training of the MHD administrative staff;
- (b) budget preparation for the above services;
- (c) conducting ICF/MR provider audits;
- (d) conducting utilization reviews of the service programs outlined above;
- (e) screening client eligibility for the above-listed services; and

- (f) maintaining a client data system;
- (g) processing vendor and provider payments;
- (h) maintaining financial accountability;
- (i) reviewing MHD administrative rules; and
- (j) providing technical support to MHD.

This basic division of responsibility will apply to the administration of waived services as well. A somewhat similar arrangement was authorized during the 1981 session of the Oregon Legislature, in a measure establishing a new Senior Services Division within the Department. This new Division will assume certain Title XIX responsibilities currently carried out by the Adult and Family Services Division.

Prepared by:

National Association of State
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December 24, 1981

Summary of Medicaid Home and Community-Based
Care Waiver Request

KANSAS

- A. Types of Waivers Requested. The Kansas Department of Social and Rehabilitation Services requested permission to pay for certain non-institutional services through the Medicaid program, and also asked for approval to waive the "statewideness" (Section 1902(a)(c)) and "comparability" (Section 1902(a)(10)) provisions for the Act.
- B. Reimbursable Services. The Kansas waiver request did not include separately defined services for mentally retarded or developmentally disabled persons; rather, all the non-institutional services proposed were applicable to all financially and otherwise eligible elderly and disabled persons in the state. The requested services include:
- Case Management: A service "...to assist the client in retaining or achieving the maximum degree of independence in daily living while assuring the individual's health, safety and emotional well-being."
 - Homemaker Services: This service "...consists of general household activities provided by a trained homemaker when the individual regularly responsible for these activities is temporarily absent or unable to manage the home and care for himself/herself or others in the home."
 - Personal Care Services: Kansas requested a waiver to provide personal care services in a manner that departs from the traditional definition. Personal care would "encompass assistance in daily living skills and personal adjustment such as meal preparation, room maintenance, arranging for referrals to mental/medical health care services as appropriate to meet the client's needs, non-medical attendant care, night support and wellness monitoring". These services would be provided in clients' homes as well as in any of the following alternative living situations:
 1. Adult Family Homes - Usually an adult family home is a private household offering assistance in daily living skills and personal adjustment for up to four (4) adult clients.
 2. Congregate Care - Similar to an adult family home except that it will serve up to eight (8) mentally retarded clients.

3. Adult Residential Services - Teach elderly and disabled people how to live on their own in the community. Some of the services to be provided are training in menu planning and meal preparation, grocery and other shopping skills, laundry skills, general housekeeping skills, budgeting, banking and comparative buying skills.
4. Non-Medical Attendant Care - It is designed to reduce the premature placement of disabled adults in costly medical facilities by providing in-home services (e.g., assistance in meal preparation, the use of appliances, bathing, dressing, etc.) for disabled individual.
5. Night Support - The purpose is to provide overnight assistance to "...elderly and disabled clients who are not able to be alone in the evening because of anticipated medical problems."
6. Medical Alert and Monitoring System - Provides "...support to the individual having a medical need which could become a crisis at any time." The medical alert is a small instrument worn by the client that, at a push of the button, alerts medical staff.
7. Wellness Monitoring - Registered nurses visit clients in their own homes or alternative living situations on a monthly basis to monitor blood pressure, breathing, pulse, and other wellness indicators, when necessary.

In all of the alternative residential settings, the residents are responsible for their room and board costs, only service costs will be reimbursable under the Medicaid waiver.

- Home Health Aide Services: "...include the performance of simple procedures such as the extension of therapy services (physical, occupational, speech), personal care, ambulation, exercise, household services essential to health care at home, assistance with medications that are ordinarily self-administered, reporting changes in the patient's condition and needs and completing appropriate records."
- Adult Day Health Services: "to provide both health and social services needed to insure the optimal functioning of the client as well as habilitation services suitable for the care of the mentally retarded and developmentally disabled." In Kansas, adult day care centers are generally attached to an adult care home, home health agency or other approved agency and may offer such services as: screening tests, nutrition information, personal hygiene, grooming and other health-related services, as well as such social services as evaluation and diagnosis, supportive therapy, crisis intervention, outreach, counseling, etc.

- Habilitation Services: "...are health and social services needed to insure the optimal functioning of the mentally retarded or persons with related conditions." Habilitation services that will be provided under the waiver program for MR/DD clients include physical therapy, occupational therapy, speech pathology, audiology, and minor physical adaptations to the home.
 - Respite Care: "...temporary short-term care for individuals who are elderly or disabled. The purpose is to give relief to the individuals or families who care for the client daily." Examples of times when respite care may be needed include "illness, fatigue, vacation or attending special functions inappropriate to the client." Respite services may be provided in the individual's own home, the respite provider's home, or in an institution.
 - Hospice Care: "...is made up of support teams of caring people who are trained in meeting the physical and emotional needs of the elderly, disabled and terminally ill clients who have a limited life expectancy, and their families."
- C. Health and Welfare Safeguards. In its request, Kansas states that "the high standards for training, certification, licensing, inspection and provision of services which are established in Kansas statutes and administrative regulations will be maintained." The pertinent regulations were included as an appendix to the waiver request. Other ways in which Kansas will protect the health and welfare of waiver beneficiaries include: monthly monitoring by the case manager; random review of case managers by the Department's Oversight Team; yearly review of the waiver program by the University of Kansas Long Term Care Gerontology Center; the utilization of licensed nurses and social workers; and review of provider records by federal staff.
- D. Financial Accountability. The Kansas Department of Social and Rehabilitation Services has contracted with the Electronic Data Systems--Federal (EDS-Federal) to expand the currently certified Medicaid Management Information System (MMIS). The funds expended on waiver services will be monitored by the Management Administrative Reporting System (MARS). The MARS will assist SRS in its requirement that the state and providers maintain financial accountability for funds expended on services offered under the waiver authority.

Specific MARS services include reports on the financial status of the waiver program, number of claims processed, number of claims paid, number of claims denied, number of recipients, number of providers participating, adequacy of service delivery, extent of service delivery, usage trends, impact analysis, status of payments and expenditure analysis.

- E. Individual Assessments and Service Eligibility. Only those beneficiaries who are eligible for a skilled nursing facility, intermediate care facility or intermediate care facility for the mentally retarded shall be offered the choice of utilizing the alternate community-based services provided under the waiver program. A pre-admission team will objectively evaluate the needs and abilities of each client who might require the level of care provided in a SNF, ICF, or ICF/MR.

The pre-admission team, composed of a licensed social worker and a registered nurse, develop a plan of care which must be approved by SRS. The pre-admission team then meets with the case manager who becomes responsible for seeing that the client receives the needed services.

The pre-admission assessment is based on the Barthel Scale. Using the Barthel score as a guide, the unique needs and abilities of each client are matched against the array of services and living arrangements potentially available in that community in order to ascertain what home and community-based alternatives may be feasible.

The case manager will review each client's plan and the services being provided, on a monthly basis, to ensure continual eligibility. Changes in the plan are made on an as-needed basis.

- F. Client Choice. The Department's Oversight Team will insure that clients who are eligible for services under the waiver are informed by the pre-admission screening team during the assessment and eligibility process of feasible alternatives for long-term care and given a choice as to which type of service to receive. The choice will include both the institutional option for which client need has been established and the feasible home and community-based care services available.

- G. Comparative Per Capita Expenditure Estimates. Estimates of the total population likely to receive waived services were developed from agency reports on the characteristics of clients currently receiving services in institutions, nursing facilities, and community settings. Estimates of Medicaid expenditures under the waiver and under the current Medicaid State Plan were developed and compared separately for clients eligible to receive and receiving Medicaid services in Title XIX certified long term care facilities.

The State's calculations are summarized in the following table.*

	FY 1983	FY 1984	FY 1985
A	14,049	14,049	14,049
B	\$730.62	\$789.07	\$852.20
C	2,569	2,819	3,319
D	\$ 63.92	\$105.84	\$133.64

* There is no separate breakdown for MR/DD clients or other eligible populations.

	FY 1983	FY 1984	FY 1985
F	<u>14,299</u>	<u>14,799</u>	<u>15,299</u>
G	\$962.69	\$1,039.71	\$1,222.89
H	2,069	2,069	2,069
I	\$ 52.67	\$ 56.88	\$ 61.43

Where:

- A = the estimated number of persons who would receive care in SNF, ICF or ICF/MR facilities if the proposed waiver is approved.
- B = the average monthly cost of an ICF, ICF/MR, or SNF resident if the waiver is approved. (N.B., the state has assumed an eight (8) percent inflation increase in both FY 1984 and FY 1985 costs).
- C = the estimated number of recipients of waived services.
- D = the estimated monthly cost for clients receiving home and community-based care services under the waiver. (N.B., this estimate is based on utilization and cost information for the current users of long term care services under consideration, assuming an eight (8) percent inflationary increase in both FY 1984 and FY 1985.)
- F = the estimated number of persons who would receive care in SNF, ICF, or ICF/MR facilities in the absence of a waiver. (These figures represent a 500 person annual increase)
- G = the average monthly cost of an ICF, ICF/MR, or SNF resident in the absence of a waiver. (N.B., Assuming eight (8) percent inflation in both FY 1984 and FY 1985.)
- H = the monthly average of persons budgeted to receive personal care and home-health services under the current Title XIX State plan, (in the absence of a waiver).
- I = the average monthly per client cost of services provided under H.

Applying these utilization and cost estimates to the mathematical formula contained in Section 441.303(d) of HHS regulations, Kansas officials conclude that the average per client expenditures for the provision of services under the waiver will not exceed the cost of services without the waiver:

FY 1983 Expenditures Under the Waiver		FY 1983 Expenditures Without the Waiver
$(14,049 \times \$730.62) + (2,569 \times \$63.92)$	$\leq$	$(14,299 \times \$730.62) + (2,069 \times \$52.67)$
$(14,299 + 2,069)$		$(14,299 + 2,069)$
$\$637.14 \leq \644.92		

Similar calculations also are included for FY 1984 and FY 1985. Kansas officials had predicted that if the waiver were not granted, the ICF (including ICF/MR) resident population would increase by 500 persons per year over the next three years.

- H. Annual Impact Reports. The Oversight Team annually will provide the Secretary of HHS with information concerning the types and amount of medical assistance provided and on the health and welfare of the beneficiaries. This information will be consistent with the data collection plan to be promulgated by HHS.
- I. Financial Eligibility. In addition to all recipients of SSI (who, by federal law, must be covered under a state's Medicaid program) Kansas plans to offer waived services to persons with income in excess of maintenance needs (protected income level) who meet the eligibility criteria for the medically needy.

The state plans to reduce Medicaid payments for home and community-based care services under its waiver program to the extent that any eligible recipient has income and resources which exceed the income disregards outlined in 42 CFR 435.726.

- J. Organizational Responsibility. The Kansas Medicaid Waiver Program will be administered by the Department of Social and Rehabilitation Services, which is the single state Medicaid agency. The programs and services covered under the waiver will be implemented, administered, and monitored by the Oversight Team. The Oversight Team is composed of Directors of four branches of SRS (Adult Services, Medical Services, Mental Health-Retardation Services, and Rehabilitation Services), as well as other SRS staff.

The Team's responsibilities include: ensuring that each of the home and community-based services is provided in a professional and cost-effective manner, routinely reviewing the programs and suggesting changes as needed, and randomly and periodically reviewing the assessments, plans of care, and services provided to individual clients.

Additional input and review will be provided by the Long Term Care Advisory Council and the University of Kansas Long Term Gerontological Center. The Long Term Care Advisory Council is a blue ribbon committee composed of the Secretary of the Department of Social and Rehabilitation Services, the Secretary of the Department on Aging, the Secretary of the Department of Health and Environment, the Secretary of the Department of Transportation, and representatives from minority groups, the League of Women Voters, the Kansas Legislature, the Nursing home industry, and various interest groups representing aged and disabled Kansans.

The main goal of the Council will be to coordinate and expedite the waiver program as it pertains to other agencies and interest groups and also to bring a variety of viewpoints to the Oversight Team. The Long Term Care Gerontology Center will provide the input of innovative and workable ideas into the home and community-based care service program, state officials indicate.

Prepared by:

National Association of State
Mental Retardation Program
Directors, Inc.

April 9, 1982



Rehabilitation Services Commission

INTER-OFFICE COMMUNICATION NO. _____

DATE June 24, 1982

DESTRUCTION DATE _____

Robert Rabe; Terry Etling, Lowell Morris, Doris Barcomb, John Caprio,
Doug DeVoe, John Connelly

From: ☐ Division of Policy and Procedures

Origin: ☒ David Cameron, Policy Development Coordinator

Subject: Final Review of Attendant Care Rules

This revised draft of the proposed attendant care rules incorporates written comments as well as the changes that were agreed on in the 6/15/82 discussion among several Central Office staff, as described below:

1. The descriptions of various fiscal/accounting systems have been deleted in favor of a very general statement in paragraph (J)(2)(c). This will give the pilot project the freedom to determine these procedures, which we then can spell out in revised rules next year.
2. The priority groups will be served exactly as they appear in paragraphs (B)(1) through (B)(4), with lower ranked groups served only as funds are available. The fifth group, made up of people who cannot work or live independently, has been deleted entirely because it does not fit with the intent of the legislation.
3. The payment schedule incorporated in these rules has been reduced to just paragraph (H), viz., the hourly rate for attendant care. All other payment considerations (overnight costs, meals for attendants, etc.) will be left to negotiation between the disabled person and the attendant.
4. A minimum need of eight consecutive weeks of attendant care has been set as an eligibility criteria in paragraph (D)(4). For the sake of cost effectiveness, this would eliminate students between quarters and those with other temporary situations.
5. Payment of any applicable income taxes or other payroll withholding costs has been added to the list of attendant's duties in paragraph (F)(2)(b). Also the rule about attendants seeking liability insurance is gone because there apparently is no such coverage available.
6. We will be filing permanent rules, not temporary ones as discussed in the 6/11/82 memo about these rules. Conversations with Representative Skeen's office revealed that permanent rules were definitely preferred. That means we need to file the proposed rules by July 8.

One reviewer brought up a concern that the minimum of fourteen hours per week may penalize some people who need just a little bit of help in order to get to work. Would cost effectiveness be a factor in this just as it is in item #4 above? There will be administrative costs in serving such a person including training the person, arranging attendants for him/her, and processing payments for services rendered. Although the individual would doubtless be benefited, if these costs outweigh the value received for the program as a whole, then the minimum hours requirement might help serve more people for the money.. What is your opinion?

Although we discussed this matter in the 6/15/82 meeting, John Connelly has since brought up his own concerns about defining the business relationship between the disabled person and the attendant: "It is important that this relationship be clarified prior to the provision of any client services. The potential for accidents is as great in the pilot project as the permanent. If the relationship is not clarified in the rule and an accident occurs which gives rise to a suit, a court rather than RSC would decide whether there is an employee-employer relationship between RSC and the attendant." What is your opinion?

I am going to share this draft with the Consumer Advisory Council's policy subcommittee on Friday, June 25. Unless that meeting reveals some major issues, we do not expect to need another meeting of RSC staff. Please try to return your comments by June 30. We know that this is again very short notice but, considering the holiday, if we have all comments in by the 30th, we'll have less than a week to get the rules polished up for filing on the 8th.

DC:dld

Attachment

c: C. Schiefer
F. Gattas
W. Herbein
✓ E. Minter
D. Wysocki
R. Schuricht

10/80

RULE SUMMARY AND FISCAL ANALYSIS

Rehabilitation Services Commission
Division of Policy and Procedures
 Agency Name

Carolyn J. Schiefer; David Cameron
 Contact Person(s)

4656 Heaton Road Cols., Ohio 43229
 Agency Address

(614)438-1230
 Phone Number(s)

3304-4-01
 Rule Number

Amendment	New Rule	Rescission
	X	

Are you proposing this rule as a result of recent legislation? yes

Bill #: Am. Sub.H.B.552 Sponsor: Representative Clifton Skeen 114th

Identify the appropriate ORC section(s) this rule amplifies: 3304.41

Estimate the total amount by which the proposed rule would increase/decrease either revenues/expenditures during the current biennium (in dollars): \$500,000

Identify the appropriation that authorizes each expenditure necessitated by the proposed rule: _____

Provide a summary of the estimated cost of compliance with the rule to all directly affected persons and the estimated cost to the rule-making agency for the administration and enforcement of this rule:

=====

Statement of purpose of proposed rule:

This new rule describes the requirements for providing personal care assistance (i.e., attendant care) to enable severely physically disabled persons to live independently or work.

3304-4-01 ATTENDANT CARE PROGRAM.

(A) FOR THE PURPOSES OF THIS RULE THE FOLLOWING DEFINITIONS ARE ESTABLISHED:

- (1) "SEVERELY PHYSICALLY DISABLED PERSON" MEANS A PERSON WHO HAS LOST THE USE OF AT LEAST TWO EXTREMITIES WITH A RESULTING LOSS OF FUNCTIONAL ABILITY.
- (2) "ATTENDANT" MEANS A PERSON WHO PROVIDES ATTENDANT CARE.
- (3) "ATTENDANT CARE" MEANS PERSONAL CARE ASSISTANCE THAT INCLUDES SERVICES TO ASSIST A SEVERELY PHYSICALLY DISABLED PERSON IN PERFORMING THE ACTIVITIES OF DAILY LIVING. SUCH ACTIVITIES MAY INCLUDE BUT ARE NOT LIMITED TO DRESSING, TOILETING, GROOMING, BATHING, PREPARING FOOD, FEEDING, TURNING, REPOSITIONING, TRANSFERRING (E.G., FROM A BED TO A WHEELCHAIR, FROM A WHEELCHAIR TO A CAR, ETC.), GIVING MEDICATION, AND ASSISTING IN AMBULATION.
- (4) "EMPLOYED" AND "EMPLOYMENT" MEANS THAT THE SEVERELY PHYSICALLY DISABLED PERSON WORKS FOR AT LEAST TWENTY HOURS PER WEEK.

(B) THE PURPOSE OF THE PROGRAM DESCRIBED IN THIS RULE SHALL BE TO PROVIDE FUNDS TO PAY FOR ATTENDANT CARE TO ENABLE ELIGIBLE SEVERELY PHYSICALLY DISABLED PERSONS TO LIVE INDEPENDENTLY OR WORK. THE REHABILITATION SERVICES COMMISSION SHALL ADMINISTER THIS PROGRAM. WHEN SUFFICIENT FUNDS ARE AVAILABLE, THOSE FOUND ELIGIBLE SHALL BE SERVED BASED ON THE RANK ORDER OF PRIORITY GROUPS LISTED BELOW:

- (1) THE FIRST PRIORITY GROUP SHALL INCLUDE PERSONS WHO ARE EMPLOYED AT LEAST TWENTY HOURS PER WEEK AND WHO NEED ATTENDANT CARE TO MAINTAIN EMPLOYMENT.
- (2) THE SECOND PRIORITY GROUP SHALL INCLUDE PERSONS WHO ARE READY FOR EMPLOYMENT BUT CANNOT ACCEPT A JOB UNLESS ATTENDANT CARE IS AVAILABLE.
- (3) THE THIRD PRIORITY GROUP SHALL INCLUDE TRAINEES WHO ARE PREPARING FOR EMPLOYMENT AND WHO NEED ATTENDANT CARE TO CONTINUE THE TRAINING.

- (4) THE FOURTH PRIORITY GROUP SHALL INCLUDE PERSONS WHO NEED ATTENDANT CARE TO LIVE INDEPENDENTLY.

(C) RSC'S ADMINISTRATION AND MANAGEMENT OF THE PROGRAM SHALL INCLUDE BUT NOT BE LIMITED TO THE FOLLOWING DUTIES AND RESPONSIBILITIES:

- (1) ESTABLISHING A NINE-MEMBER ADVISORY/STEERING COMMITTEE MADE UP OF FIVE CONSUMERS AND FOUR REPRESENTATIVES FROM HUMAN SERVICE ORGANIZATIONS TO PROVIDE ONGOING EVALUATION AND ADVICE ON THE OPERATION OF THE PROGRAM.
- (2) ESTABLISHING PAY RATES FOR ATTENDANTS.
- (3) CHOOSING FACILITIES AND NEGOTIATING TERMS WITH THEM FOR OPERATING THE PROGRAM AT THE LOCAL LEVEL, AS DESCRIBED IN PARAGRAPHS (E) TO (E)(11).
- (4) HELPING FACILITIES RECRUIT ATTENDANTS AND FIND APPROPRIATE SEVERELY PHYSICALLY DISABLED PERSONS TO APPLY FOR ATTENDANT CARE.
- (5) DETERMINING A PERSON'S ELIGIBILITY TO RECEIVE ATTENDANT CARE UNDER THE PROGRAM BASED ON THE ASSESSMENT PERFORMED BY THE FACILITY (DESCRIBED IN PARAGRAPHS (E)(2) TO (E)(4) AND (E)(8)).
- (6) PERIODICALLY EVALUATING THE PROGRAM TO ENSURE EFFICIENCY AND TO DETERMINE WAYS TO IMPROVE ITS EFFECTIVENESS.

(D) TO BE ELIGIBLE FOR ATTENDANT CARE, A PERSON SHALL:

- (1) BE EIGHTEEN YEARS OLD OR OLDER.
- (2) BE SEVERELY PHYSICALLY DISABLED.
- (3) NOT BE ELIGIBLE FOR ATTENDANT CARE FROM RSC'S VOCATIONAL REHABILITATION PROGRAM OR FROM ANY OTHER STATE OR FEDERAL PROGRAM.
- (4) NEED NOT LESS THAN EIGHT CONSECUTIVE WEEKS OF ATTENDANT CARE.
- (5) NEED NOT LESS THAN FOURTEEN HOURS OF ATTENDANT CARE PER WEEK.

- (6) NEED NOT MORE THAN THIRTY-FIVE HOURS OF ATTENDANT CARE PER WEEK FROM THIS PROGRAM. IF THE PERSON NEEDS MORE THAN THIS MAXIMUM, HE/SHE SHALL BE INELIGIBLE FOR ASSISTANCE UNDER THIS PROGRAM UNLESS HE/SHE CAN PAY FOR THE ADDITIONAL SERVICES NEEDED OR CAN ARRANGE TO HAVE THEM PROVIDED BY ANOTHER SOURCE.
- (7) HAVE TOTAL GROSS ANNUAL INCOME OF LESS THAN \$30,000.
- (8) HAVE BEEN DETERMINED CAPABLE OF INSTRUCTING AND SUPERVISING ATTENDANTS, AS DESCRIBED IN PARAGRAPH (E)(3).
- (9) BE LIVING, OR THROUGH THIS PROGRAM BE ABLE TO LIVE, INDEPENDENT OF HIS/HER FAMILY OR OF AN INSTITUTION.
- (10) AGREE THAT HIS/HER NEED FOR CONTINUING ATTENDANT CARE SHALL BE SUBJECT TO PERIODIC EVALUATION.

(E) FOR RSC TO CHOOSE A FACILITY TO OPERATE THIS ATTENDANT CARE PROGRAM AT THE LOCAL LEVEL, THAT FACILITY SHALL BE NON-PROFIT AND, AS ITS PURPOSE, SHALL EXIST AT LEAST IN PART TO PROVIDE SERVICES TO PERSONS WITH DISABILITIES. THE FACILITY'S DUTIES AND RESPONSIBILITIES SHALL INCLUDE BUT NOT BE LIMITED TO:

- (1) LOCATING SEVERELY PHYSICALLY DISABLED PERSONS WHO MAY BE ELIGIBLE FOR THE PROGRAM.
- (2) PRE-SCREENING THE PERSON ACCORDING TO THE CRITERIA IN PARAGRAPHS (D) TO (D)(9) BY USING A CHECKLIST AND GUIDE TO ATTENDANT CARE AS PRESCRIBED BY RSC.
- (3) ASSESSING THE PERSON'S APPROPRIATENESS TO RECEIVE ATTENDANT CARE THROUGH THIS PROGRAM; THE ASSESSMENT SHALL INCLUDE BUT NOT BE LIMITED TO DETERMINING THE ABILITY TO INSTRUCT AND SUPERVISE ATTENDANTS, AND TO MAINTAIN SCHEDULES AND RECORDS.
- (4) ASSESSING THE PERSON'S ATTENDANT CARE NEEDS.
- (5) RECRUITING POTENTIAL ATTENDANTS AND REFERRING THEM TO ELIGIBLE PERSONS.
- (6) PROVIDING INFORMATION TO ELIGIBLE PERSONS ABOUT THE SKILLS NEEDED TO INSTRUCT AND SUPERVISE ATTENDANTS.

- (7) ORIENTING ATTENDANTS TO THE GENERAL DUTIES AND RESPONSIBILITIES OF AN ATTENDANT.
 - (8) PERIODICALLY EVALUATING EACH ELIGIBLE PERSON'S NEED FOR CONTINUED ATTENDANT CARE.
 - (9) MAINTAINING A POOL OF ATTENDANTS TO CHOOSE FROM FOR HIRING PURPOSES AND FOR SERVING IN SUBSTITUTE AND/OR EMERGENCY SITUATIONS.
 - (10) SERVING THE COMMUNITY AS AN INFORMATION RESOURCE ON ATTENDANT CARE.
 - (11) PROVIDING INFORMATION AND REFERRAL SERVICES ABOUT OTHER FINANCIAL ASSISTANCE AND/OR SOCIAL SERVICE PROGRAMS THAT, BY SUPPLEMENTING THE ATTENDANT CARE PROGRAM, MAY FURTHER ASSIST SEVERELY PHYSICALLY DISABLED PERSONS TOWARD INDEPENDENT LIVING.
- (F) PARAGRAPHS (F)(1) TO (F)(1)(d) OF THIS RULE DESCRIBE THE QUALIFICATIONS FOR AN ATTENDANT AND PARAGRAPHS (F)(2) TO (F)(2)(f) DESCRIBE AN ATTENDANT'S RESPONSIBILITIES:
- (1) TO BE CONSIDERED TO WORK AS AN ATTENDANT UNDER THIS PROGRAM, A PERSON SHALL:
 - (a) BE EIGHTEEN YEARS OLD OR OLDER.
 - (b) BE ABLE TO MEET THE PHYSICAL AND MENTAL DEMANDS OF PROVIDING ATTENDANT CARE.
 - (c) BE DEPENDABLE, STABLE, AND ABLE TO DEAL WITH EMERGENCIES, AS ASSESSED BY THE FACILITY.
 - (d) NOT BE A RELATIVE LIVING IN THE SAME HOUSEHOLD OR AN IMMEDIATE FAMILY MEMBER.
 - (2) THE ATTENDANT'S RESPONSIBILITIES SHALL INCLUDE BUT NOT BE LIMITED TO:
 - (a) AGREEING TO THE TERMS OF EMPLOYMENT AS SPECIFIED BY THE ELIGIBLE PERSON.
 - (b) PAYING ANY APPLICABLE FEDERAL, STATE, OR LOCAL TAXES ON WAGES PAID THROUGH THIS PROGRAM.

- (c) PERFORMING THE TASKS AGREED ON WITH THE ELIGIBLE PERSON.
 - (d) PERFORMING TASKS WITH CARE TO AVOID INJURY AND/OR DISCOMFORT TO THE ELIGIBLE PERSON.
 - (e) REPORTING TO WORK AS SCHEDULED.
 - (f) MAINTAINING THE PRIVACY OF THE ELIGIBLE PERSON.
- (G) THE ELIGIBLE PERSON'S RESPONSIBILITIES SHALL INCLUDE BUT NOT BE LIMITED TO:
- (1) INSTRUCTING AND SUPERVISING ATTENDANTS.
 - (2) DISCUSSING AND COMING TO AGREEMENT WITH EACH ATTENDANT AS TO WHAT SERVICES ARE TO BE PROVIDED.
- (H) THE RATE OF PAYMENT FOR ATTENDANT CARE UNDER THIS PROGRAM SHALL BE A MAXIMUM OF \$4.50 PER HOUR.
- (I) WHEN A PERSON WHO HAS APPLIED FOR ATTENDANT CARE IS DETERMINED INELIGIBLE OR WHEN AN ELIGIBLE PERSON WHO IS RECEIVING SERVICES UNDER THE PROGRAM DISAGREES WITH ANY ACTION OR DECISION MADE BY RSC OR BY A FACILITY, HE/SHE MAY REQUEST AN ADMINISTRATIVE REVIEW BY THE MANAGER OF RSC'S DIVISION OF COMMUNITY RESOURCES; IF NOT SATISFIED WITH THE RESULTS, HE/SHE MAY REQUEST A FAIR HEARING WITH THE RSC ADMINISTRATOR. TIME FRAMES AND ALL OTHER PROCEDURES CONCERNING ADMINISTRATIVE REVIEWS AND FAIR HEARINGS SHALL BE THE SAME AS THOSE DESCRIBED FOR VOCATIONAL REHABILITATION APPLICANTS/CLIENTS UNDER RULE 3304-2-04 (EXCEPT PARAGRAPHS (B) AND (F)) OF THE ADMINISTRATIVE CODE.
- (J) RSC SHALL ADMINISTER THIS PROGRAM AS A PILOT PROJECT FOR THE PURPOSES OF DETERMINING THE MOST EFFICIENT METHODS OF OPERATION, AS DESCRIBED IN PARAGRAPHS (J)(1) TO (J)(3):
- (1) ELIGIBLE PERSONS SHALL RECEIVE PAYMENT FOR ATTENDANT CARE COSTS INCURRED AFTER ALL OF THE FOLLOWING HAVE BEEN ACCOMPLISHED BUT NOT BEFORE OCTOBER 1, 1982:
 - (a) RSC HAS CHOSEN FACILITIES AND NEGOTIATED TERMS WITH THEM FOR THE OPERATION OF THE PROGRAM AT THE LOCAL LEVEL.

- (b) THE FACILITIES HAVE FOUND APPROPRIATE SEVERELY PHYSICALLY DISABLED PERSONS AND ASSESSED THEIR ATTENDANT CARE NEEDS IN PREPARATION FOR RECOMMENDING THEM FOR ELIGIBILITY.
 - (c) THE FACILITIES HAVE RECRUITED ATTENDANTS AND ORIENTED THEM TO THEIR DUTIES AND RESPONSIBILITIES.
- (2) THE OPERATION OF THE PILOT PROJECT SHALL INCLUDE BUT NOT BE LIMITED TO THE FOLLOWING PROCEDURES:
- (a) RSC SHALL DESIGNATE A PILOT PROJECT DIRECTOR.
 - (b) RSC SHALL CHOOSE FACILITIES LOCATED BOTH IN SMALL TOWN/RURAL AREAS AND IN URBAN AREAS TO OPERATE THE PILOT PROJECT AT THE LOCAL LEVEL.
 - (c) RSC SHALL ESTABLISH VARIOUS FISCAL AND ACCOUNTING PROCEDURES FOR PROVIDING FUNDS TO THE ELIGIBLE PERSON, THE ATTENDANT, AND/OR THE FACILITY TO PAY FOR ATTENDANT CARE EXPENSES DURING THE PILOT PROJECT.
 - (d) DURING THE PILOT PROJECT, THE DIRECTOR OF RSC'S BUREAU OF PROGRAM SUPPORT, RATHER THAN THE MANAGER OF RSC'S DIVISION OF COMMUNITY RESOURCES AS STATED IN PARAGRAPH (I) OF THIS RULE, SHALL CONDUCT AN ADMINISTRATIVE REVIEW OF ANY APPEAL. ALL OTHER PROCEDURES LISTED IN PARAGRAPH (I) OF THIS RULE APPLY DURING THE PILOT PROJECT.
- (3) THE PILOT PROJECT SHALL END WHEN RSC DETERMINES THAT THE PROGRAM IS READY TO SERVE SEVERELY PHYSICALLY DISABLED PERSONS THROUGHOUT THE STATE OR ON SEPTEMBER 30, 1983, WHICHEVER COMES FIRST.

EFFECTIVE: _____

REPLACES : _____

Certification

Date

 Rehabilitation Services Commission

INTER-OFFICE COMMUNICATION NO. _____

DATE June 4, 1982

DESTRUCTION DATE _____

To: John Caprio, Chief, Consumer Affairs

From:  Douglas V. DeVoe, Chief, Division of Finance

Origin: 

Subject: Payments for Attendant Care Services

I met with Bill Lenkey of the State Auditor's office last week to discuss Attendant Care. In general we discussed three primary means of payment.

- 1) Payment directly to the client.
- 2) Payment to a facility who pays the attendant.
- 3) Payment to the attendant.

I indicated that the agency preference was payment to the client. Bill had several reservations. First, he was concerned about the audit trail to indicate the attendant services were actually being provided as paid to the client. Second, he was concerned about the obligation of the client for personal tax purposes. The client would, because of the amount, receive an annual notification of earnings (1099 form) and have those amounts reported to IRS. Third, he had concerns about the ability of the client to maintain payroll records along with appropriate federal, state, and local taxes, workers compensation, unemployment compensation, etc. Related to this is the concern that the attendant who is the subject of the records may also assist in maintaining them and that there is a potential for fraud.

Bill indicated a preference that we provide facilities with a corpus, ask them to hire and pay attendants from the corpus, and maintain records for audit. Second preference would be direct contract with the attendant, recognizing that facility payment would involve increased administrative cost for RSC. Bill would like a follow-up meeting with a Deputy State Auditor involved, as well as attendant care program staff to address this again once we decide the system of payment we desire. Under any system, Bill is concerned about who will audit the payments and when.

My preference would be a three-party contract with the attendant and the client with direct payment to the attendant from a time sheet maintained by the client and signed by the client and the attendant, processed on a two-week pay period. I'm concerned that facility payment will increase administrative costs beyond the scope of the budget outlined to the Controlling Board and could jeopardize future funding.

My reservations about client payment probably are a result of my experiences in B.E. where auditors were almost never able to reconstruct a complete audit trail for operators with considerable more training in record keeping and with monthly supervision from agency staff. I'm afraid we may create an auditing nightmare we could never resolve.

I think we should meet again at the earliest convenience to discuss this again and make a final determination of preference so we may begin assembling sample documents for record keeping, resolve client tax responsibilities with IRS, and proceed with planning.

c: R. Rabe
T. Etling

May 13, 1982

TO: Chairmen of Community Workshops on Attendant Care - Doris Brennan, Alice Sporar, Cleveland; Joyce Quinliven, Toledo; Roger Flint, Dayton; John Latcham, Phyllis Elmo, Youngstown; Sue Mahler, Jess Davidson, Columbus; Larry Rossiter, Cincinnati; Gwen Callas, Jerry Snyder, Kent-Akron

FROM: Francis J. Gattas, Director, Office of Consumer Affairs

On November 19, 1981, the 114th Ohio General Assembly Enacted Am. Sub. H.B. 552, Sec. 3304.41, which stated:

"The Rehabilitation Services Commission shall establish and administer a program for the use of funds appropriated for that purpose to provide personal care assistance to enable eligible severely physically disabled persons to live independantly or work, shall adopt rules in accordance with Chapter 119 of the Revised Code as necessary to carry out the purposes of this section and shall apply to the Controlling Board for the release of the funds."

In December, RSC went to the Controlling Board in request of funds to initiate the program. The decision of the Board was deferred until a program plan (proposal) was developed.

On January 16, RSC hosted a meeting of consumers and some professionals to provide input into the development of the proposal. On April 15th, the group met again to discuss the draft proposal. (Attached is the finished product). On May 10, RSC again went before the Controlling Board in request of funds. THE CONTROLLING BOARD, UNANIMOUS IN THEIR DECISION, WILL RELEASE \$500,000 JULY 1, 1982 THRU JUNE 30, 1983 FOR THE DEVELOPMENT OF AN ATTENDANT CARE PROGRAM.

The funds will be released to RSC as follows:

July 1 thru Sept. 30 (1982) - \$ 20,000
Oct. 1 thru Dec. 31 (1982) - 77,000
Jan. 1 thru Mar. 31 (1983) - 128,000
Apr. 1 thru June 30 (1983) - 275,000

All the work done since the 1980 April state workshop in Columbus on attendant care...the follow-up community workshops, developing the legislation, the evolution of ADO, and the consumer lobbying...has paid off! The legislation and the funding of the Ohio personal attendant care program is certainly the result of the statewide coordinated grassroots movement for such a program. Consumers have certainly impacted upon the legislature! Please share this good news with other consumers within your respective communities. Certainly many consumers will be contacting their local representatives thanking them for their support of the attendant care program.

For those who may also wish to write to members of the Controlling Board:

Senator Stanley Aranoff - Cincinnati
Senator William Bowen - Cincinnati
Senator Ted Gray - Columbus

Representative Cliff Skeen - Akron
Representative Robert Netzley - Laura
Representative Myrl H. Shoemaker - Bourneville

Address: Ohio State House
Columbus, Ohio 43215

OVER

The following are those who participated in one or both of the meetings held on 1/15/82 or 4/15/82.

Consumers:

Bill Schultz - President, Advocates for Disabled Ohioans, Kent, Ohio
Doris Brennan - Cleveland, Services for Independent Living
Larry Rossiter - Dept. of Physical Medicine, University of Cincinnati
Roger Flint - Dayton
Linda Gerraci - Cincinnati
Mary Verdi - Services for Independent Living, Cleveland

Others:

Stan Sells - Ohio Dept. of Welfare
Martin Williams - Ohio Dept. of Welfare
Doris Combs - Dept. of Welfare, Summit County
Lynn Benjamin - Total Living Concepts, Cincinnati
Bob Strother - Cleveland
Gwen Callas - Kent State University
Donna Stauch - Dodd Hall, Columbus
Joyce Quinliven - Toledo Society for the Handicapped
Marcia Cooper - Ohio Legislative Commission
E. Minteer - RSC
H. Radde - RSC
C. Schieffer - RSC
J. Caprio - RSC
R. Schuricht - RSC
D. Cameron - RSC
T. Etling - RSC
R. Rabe - RSC

OHIO REHABILITATION SERVICES COMMISSION

A PLAN FOR A PERSONAL CARE ASSISTANCE (ATTENDANT CARE) PROGRAM

5/10/82

OHIO REHABILITATION SERVICES COMMISSION

A PLAN FOR A PERSONAL CARE ASSISTANCE (ATTENDANT CARE) PROGRAM

I PREFACE

On November 19, 1981, the 114th Ohio General Assembly Enacted Am. Sub H.B. 552, Sec. 3304.41, which stated:

"The Rehabilitation Services Commission shall establish and administer a program for the use of funds appropriated for that purpose to provide personal care assistance to enable eligible severely physically disabled persons to live independently or work, shall adopt rules in accordance with Chapter 119 of the Revised Code as necessary to carry out the purposes of this section and shall apply to the Controlling Board for the release of the funds."

The purpose of this document prepared by the Ohio Rehabilitation Services Commission (RSC) is as follows:

- (1) To establish an Attendant Care Program for Ohio.
- (2) To provide for the organization and administration of the Attendant Care Program.
- (3) To formulate administrative rules to be adopted in accordance with Chapter 119 of the Ohio Revised Code, and
- (4) To meet the application requirement by the Ohio Controlling Board for the release of funds based on program approval.

RSC would develop the attendant care program in phases, or stages, contingent on state funds appropriated for the program. Priority and stages in development would be as follows:

- Difficult to document actual work - assist to paid state*
- (1) For disabled persons who are employed and need attendant care to maintain employment.
 - (2) For employable disabled persons seeking employment contingent on availability of attendant care services
 - (3) For program eligible students and trainees with an employment goal - *what about when not in training?*
 - (4) For disabled persons to live independently
 - (5) For disabled persons living at home in need of attendant care services, but not able to be employed or live independently *should be eligible*
- no longer eligible as elig - to attend work*

II DEFINITIONS

"Administrative Agency" refers to the Ohio Rehabilitation Services Commission hereafter referred to as RSC.

"Personal Care Assistance" or "Attendant Care", are those services, as designated in RSC's "Checklist and Guide to Attendant Care Services", provided by an attendant to assist a severely disabled person in performing the activities of daily living. The attendant care services may include, but not limited to, help in the performance of routine bodily functions: dressing, toileting, grooming, bathing; preparing food; feeding; turning, repositioning, and transferring a person; giving medications; assisting in ambulation or other permissible activities agreed upon between the disabled person and the attendant in the employer-employee relationship. The services would be those appropriate for a non-medical or non-family member to perform.

(2) (3)

Change family definition

"Attendant" refers to qualified individuals employed and trained by a disabled person to provide the agreed upon personal care assistance.

- . "Night Attendant" refers to provider of attendant care services during the sleeping hours, such as repositioning and other bodily needs.
- . "Live-in Provider" refers to an attendant who lives in the recipient's home expressly for the purpose of providing attendant care services.

"Independent Living" allows disabled persons to live with as much direction and control over their own lives as possible.

"Independent Living Center" is a voluntary nonprofit resource facility, staffed and managed primarily by persons with disabilities, that offers a number of services to disabled persons to assist them in independent living. The centers may have been established, in part, with competitive grant funds from Title VII, Part B, of the 1978 amendments to the Vocational Rehabilitation Act of 1973.

"Severely Disabled Persons", defined for the purpose of this program, refers to a person who has lost the use of at least two extremities (arms or legs) and whose functional ability is limited by that loss. Such a severe physical disability can have a number of causes, including spinal cord injury, muscular dystrophy, multiple sclerosis, cerebral palsy, polio, spina bifida, amputation, arthritis, rheumatism, Parkinson's disease, hemophilia, and stroke.

"Community-based Facility" is a non-profit organization which, in part, functions as a provider and/or vendor of services.

"Employed" refers to paid employment for at least 20 hours per week.

"Program Participant" or "Program Recipient" refers to a severely disabled person determined eligible to participate in this program.

III PROGRAM GOALS AND OBJECTIVES

Although several other states have personal assistance care programs, a public subsidized program in Ohio will, essentially, be a new venture. Since the State Controlling Board will only be able to appropriate funds for the remainder of the current biennium to end June 30, 1983, the following goals are planned to be achieved in this period contingent on the amount of initial funds appropriated:

1. To demonstrate the feasibility of a personal assistance care program on a pilot project basis.
2. To focus initially on several local projects, involving both rural and urban communities, rather than a statewide effort.
3. To involve local nonprofit facilities and local field offices of RSC Bureau of Vocational Rehabilitation (BVR) and Bureau of Services for the Visually Impaired (BSVI) in exploring the best models for service delivery.
4. To refine the model(s) for further expansion throughout the state as additional funds are appropriated in subsequent years.

5. To formulate criteria and standards for participant eligibility, attendant qualifications, and community-based facility participant.
6. To resolve a workable method of "reimbursing" the program participant with funds to pay the attendant for hours worked.
7. To use the dollars received from the State Controlling Board to maximize the number of attendant hours and to serve the greatest number possible.

IV PROGRAM OVERVIEW: HOW IT WOULD WORK

A. Program Organization/Structure:

- . RSC, as the administrative agency, would designate a project director and provide the necessary clerical and support services.
- . At least two urban and two rural facilities and corresponding field units of BVR and BSVI would be invited to participate in the program. The local RSC offices with assistance from the community-based facility would serve as a resource in locating program participants, assist in the recruiting and preliminary training of attendants and assist the participants to become effective employers and trainers of attendants. The facilities would conduct a preliminary assessment of a participant applicant to determine qualifications to participate in the program and an assessment of attendant needs. Final eligibility determination of the participants would be made by RSC.
- . The program participants would be trained to be employers of the attendants. This would entail training, supervising, time record-keeping, payroll computing, tax withholding, and paycheck writing. The participant would also outline the duties or work expectations from the attendant.
- . The attendants would receive preliminary orientation by the facilities and additional instruction by the participant to meet special needs. The attendant would agree to the terms of employment (time, hours, duties, etc.).

B. Duties and Responsibilities of RSC

As the administrative unit for the attendant care program, RSC duties would include, but not be limited to:

- . Implement the program according to an approval plan
- . Assume fiscal accountability for the state funds designated for the program
- . Designate a project director or coordinator
- . Assign necessary clerical and support personnel
- . Promulgate and adopt administrative rules and guidelines

- . Establish policy and rate of pay for hourly day attendants, night attendants or live-in providers. Policy would address minimum hours, hourly rates, allowance to participant for attendant food/meals, and room and board consideration for live-in providers.
- . Select communities and the facilities and local BVR/BSVI units to participate in the program. Negotiate written agreements or memoranda of understandings.
- . Make final determination of applicant eligibility to participate in the program.
- . Establish and implement a procedure for attendant payment. Adopt guidelines relating to frequency of payment and option for participant to supplement pay to attendant. Monies would go to the participants who, in turn, would pay the attendants. This would support the employer-employee relationship between the participant and the attendant.
- . Prepare a "Checklist and Guide to Attendant Care Services".
- . Observe other management practices, including program evaluation, to assure effective and efficient program operation.

C. Duties and Responsibilities of the Community-based Facility

Contingent on working agreements, a facility may be expected to include, but not be limited to, the following:

- . Assist in program outreach for applicants who may be eligible to participate in the program.
- . Prescreen applicants (age, disability, financial need, employment status, etc.).
- . Conduct an assessment of the applicant's qualifications to participate in the program (his/her ability to instruct or supervise the attendant; ability to handle the business aspect (withholding taxes, paying the attendant, etc.); and an assessment of personal care needs that the attendant would be expected to serve.
- . Assist with the recruitment of attendant applicants and refer to participants to screen, interview and employ.
- . Assist with providing participants with skills helpful to employ and maintain the services of attendants.
- . Assist attendants, or attendant applicants with general orientation involved in serving as an attendant.
- . Provide a list to participants of attendants who may be available for substitute or emergency use; maintain a pool of attendants.
- . Serve as a community information resource on attendant care.
- . Provide information to participants and applicants on other resources that may supplement attendant care and help the individuals to obtain those services.

D. Duties and Responsibilities of the Program Participant

The participant would include, but not be limited to, the following:

- . Screen, interview and employ the attendant(s).
- . Outline and agree to specific attendant duties and job tasks; adhere to the agreement.
- . Provide the instruction or education required by the attendant to meet the participants special personal assistance needs; provide supervision.
- . Schedule attendant hours; keep time records; submit invoices for pay reimbursement; pay attendants(s); and meet other applicable employer obligations.

E. Duties and Responsibilities of the Attendant

The attendant duties would include, but not be limited to, the following:

- . Agree to terms of employment.
- . Carry out agreed duties and job tasks.
- . Report to work as scheduled.
- . Observe care to prevent participant injury when providing assistance.
- . Consider liability protection (insurance).

V SPECIFIC CRITERIA, QUALIFICATIONS AND PROCEDURES

A. Participating Community-based Facility Qualifications

Participating facilities would meet the following qualifications:

- . A non-profit facility
- . A facility whose purpose is to provide services to persons with disabilities
- . A facility who has provided, or has expressed interest in providing, attendant care services for disabled persons
- . A facility capable of carrying out and meeting the obligated responsibilities and duties

B. Eligibility Criteria for Individual Participants

Criteria to be considered in determining eligibility of participants would include the following:

- . Be at least 18 years of age
- . Be severely physically disabled

Draft

Ohio Legislative Service Commission
David A. Johnston, Director
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FINANCIAL ASSISTANCE FOR PERSONAL CARE SERVICES
FOR SEVERELY PHYSICALLY DISABLED PERSONS

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SUMMARY

I. Background Information

According to severely physically disabled persons, i.e. persons who have lost the use of at least two limbs and whose functional ability is limited by that loss, and to persons who work with them, additional financial assistance with personal, or attendant, care services is needed by severely physically disabled persons who want to work and/or live independently. Personal care services are those services that assist a person in performing the activities of daily living.

In response to this statement of need, the Legislative Service Commission approved the 113th General Assembly's request for a study of the relative costs and benefits of a program to provide personal care services to severely physically disabled persons. The staff conducting the study was also charged with evaluating several alternative designs for a state subsidy program and considering what agencies might administer such a program.

This report presents the staff's findings concerning the availability of financial assistance in Ohio, attendant care programs in other states, and program alternatives that could be used in this state. On November 19, 1981, the 114th General Assembly enacted Am. Sub. H.B. 552, which contained a requirement that the Rehabilitation Services Commission establish and administer a program to provide personal care assistance to enable eligible severely physically disabled persons to live independently or work. The question of what state agency or agencies should administer a state subsidy program is thus moot.

II. Staff Conclusions

A governmental entity that subsidizes personal care services for severely physically disabled persons might experience financial benefits as a result of deinstitutionalization of some recipients and tax revenues from others who are employed. Recipients could gain the psychological benefits of having control over their lives and using their skills and talents to their maximum potential. Families of recipients could experience a lessening of stress and tension, and some members could return to their careers and interests. On the other hand, a subsidy program might not be cost effective, and, if not well organized, it could be difficult to administer. Additionally, Ohio might not have enough attendants, accessible housing, and jobs to meet the needs of its severely physically disabled population.

Financial assistance for personal care services is limited in Ohio and is inadequate to meet the needs of the state's severely physically disabled citizens, especially those who want to work and/or live independently. The demand for this assistance is great among those persons and professionals who work with them. Additional assistance is needed if severely physically disabled persons are to lead more independent lives and/or enter the job market. This report presents alternatives in Chapter 9 for administering a financial assistance program; they include suggestions concerning possible funding sources, persons to be served, the process for evaluating applicants, income eligibility, use of other available public moneys, and services to be provided.

III. Review of Financial Assistance in Ohio and Programs in Other States

The Ohio Rehabilitation Services Commission (RSC) provides services for severely physically disabled Ohioans; it receives approximately 14% of its moneys from the state and the remainder from the federal government. Part B of Title VII of the 1978 amendments to the federal Rehabilitation Act of 1973

creates a competitive grants program for independent living centers (ILC's), i.e. resource facilities offering services, including assistance with personal care services, to disabled persons to help them live independently. In Ohio a specially designated Office in RSC coordinates the ILC program. Two ILC's are currently operating in Cleveland and Cincinnati. The Bureau of Vocational Rehabilitation (BVR) and the Bureau of Services for the Visually Impaired (BSVI) in RSC, under federal guidance, focus on providing rehabilitation services for disabled people with vocational potential. As part of their program, BVR and BSVI pay for attendant care only while clients are in the program. Demonstration programs grants, which might be used to fund a personal care services pilot project, are the only other federal rehabilitation moneys available for attendant care. Ohio has not applied for such a grant.

Title XX is a federal program through which states may use federal moneys to provide social services to their citizens. Prior to the enactment of the federal Omnibus Budget Reconciliation Act of 1981, Title XX provisions included the distribution of funds to states on a reimbursement basis, a requirement of matching funds, income eligibility criteria, and a requirement that fees for services be charged under certain circumstances. The Omnibus Act eliminated these provisions. The Department of Public Welfare administers Ohio's Title XX comprehensive services program plan, which was developed prior to the enactment of the Omnibus Act. Services are provided through county welfare departments. The Department uses Title XX moneys to provide homemaker/home health aide and chore services, both of which can be used to assist with attendant care. Title XX moneys are also used to support an Assistance for Independent Living Program through the Commission on Aging. Under changes in Title XX resulting from the Omnibus Budget Reconciliation Act, Ohio could develop an attendant care services program for severely physically disabled

persons. However, this would entail reducing funds for other services currently in existence.

Medicaid provides reimbursement for certain medical services, including home health care, provided to eligible persons. Federal law provides that SSI recipients are eligible for Medicaid and requires the cost of attendant care to be excluded from the earned income of a recipient of SSI. This exclusion is not a part of Ohio's Medicaid program because Ohio requires a recipient of SSI to meet additional criteria in order to be eligible for Medicaid. Two Medicaid services could provide attendant care services to a severely physically disabled person. The first of these is home health care, and the second is personal care, an optional Medicaid service not offered in Ohio's program.

Two recent federal changes in Medicaid could affect the program's ability to provide attendant care services for severely physically disabled persons. The first is the new option of providing home or community-based services, which might increase the availability of attendant care. However, the second, the imposition of reductions in federal Medicaid expenditures, may counteract the potentially positive effects of the first change. Medicaid in Ohio is not an ideal source of funds for personal care services because, if those services are funded through it, they must be provided by home health agencies, and there are limitations with these agencies. Additionally, Medicaid eligibility is income-based, and recipients of attendant care through Medicaid lack certain elements of control over its provision.

Persons who qualify for social security disability insurance (SSDI) and have been receiving benefits under it for at least two years are eligible to receive Medicare, which provides home health services, among others, in accordance with federal guidelines. SSDI provides monthly cash benefits to insured workers who meet eligibility requirements concerning length of previous

employment, severity of disability, and inability to work. Medicare is a national health insurance program available to recipients of SSDI, among others, without regard to income. It only provides coverage for home health care visits if the recipient needs part-time or intermittent skilled care, is homebound, and has the services prescribed by a physician. Medicare is probably not a viable source of funding for personal care attendants for severely physically disabled persons because of the above restrictions.

Limited federal assistance for personal care services is available from the Veterans Administration through an allowance for aid and attendants, from the Department of Housing and Urban Development through subsidized housing, and from ACTION through programs using senior citizens to provide care. The Bureau of Workers' Compensation pays for personal care services for persons injured on the job if their need is verified by a physician. Ohio's state universities provide varying degrees of help in locating attendants for severely physically disabled students; the Ohio Rehabilitation Center at Ohio State University helps locate and train attendants for patients who are leaving. Local governments do not provide funds for personal care services. The only applicable assistance from Ohio's hospitals that have rehabilitation inpatient units is referral and occasional training of attendants. No consumer groups provide funding, and only a few help with locating attendants. No insurance companies in Ohio will pay for personal care services rendered by nonmedical persons.

Of the nine states whose attendant care programs are described in this report, Massachusetts uses Medicaid moneys as a funding source, California and Alabama use Title XX moneys, and Rhode Island uses federal Title VII B moneys. Massachusetts, Alabama, and Rhode Island also use state moneys to subsidize personal care services as do Maine, Vermont, Washington, Connecticut, and Illinois.

CHAPTER 1. INTRODUCTION

This report was prepared in response to Legislative Service Commission approval of the Ohio General Assembly's request for a study of the relative costs and benefits of a program to provide personal care services to severely physically disabled persons. Amended H.J.R. 91 of the 113th General Assembly, sponsored by Representative John Begala and others, requested the Commission to study the relative costs and benefits of establishing state subsidies to provide personal care services for severely physically disabled Ohioans, including subsidies that would qualify for federal participation, to evaluate several alternative designs for a state subsidy program, and to consider what agencies might administer a program.

Following the resolution's approval, the Commission staff began preparing this report. The resolution did not call for the appointment of a study committee, and, in the absence of such a committee, the staff submitted this report directly to the Commission. This report thus consists of staff findings and conclusions. It does not represent the findings and opinions of the Legislative Service Commission.

I. Background Information

Human disabilities are numerous and varied; they include orthopedic impairments, blindness, deafness, personality disorders, and mental retardation. The disability group that is the focus of this study is severely physically disabled people, defined for the study's purposes as persons who have lost the use of at least two limbs and whose functional ability is limited by that loss. Such a severe physical disability can have a number

of causes, including spinal cord injury, muscular dystrophy, multiple sclerosis, cerebral palsy, polio, spina bifida, amputation, arthritis, rheumatism, Parkinson's disease, hemophilia, and stroke.

Frequently, persons who are severely physically disabled need personal, or attendant, care services, i.e. those services that assist a person in performing the activities of daily living. Personal care services could include help in the performance of routine bodily functions; dressing; grooming; bathing; the preparation and consumption of food; turning, repositioning, and transferring a person; use of medications; and ambulation. This study is concerned with the provision of personal care services to severely physically disabled persons who need them.

The broad range of disabilities that can affect persons, combined with a dearth of research on the number of disabled Americans, makes estimating the number of persons affected by a specific disability a difficult if not impossible task. No definitive statistics exist on the number of severely physically disabled Ohioans, but some general information is available. The Bureau of the Census' 1976 Survey of Income and Education, which was based on 1970 population figures, estimated that 1,410,000 Ohioans, or 14.1% of the state's population, had a "limiting health condition," a term that is broader than a severe physical disability. A second limitation with the Survey is that it did not include persons in institutions or children under three years of age. In its 1975 Ohio Disability Incidence/Prevalence Study, the Ohio Rehabilitation Services Commission (RSC) estimated the statewide average disability rate at almost 6%, or over 656,000 persons. It also estimated that, of these, more than 231,000 persons experienced orthopedic impairments or amputations; they constituted 2.2% of Ohioans. The Study omitted institutionalized persons.

Even more difficulty exists in attempting to estimate the number of severely physically disabled persons who need personal care services. A 1972 Social Security Survey of Disabled and Non-Disabled Adults estimated that 1.4% of noninstitutionalized Americans aged 20 to 64, or 1,534,000 persons, needed assistance with personal care activities. RSC estimated in 1981 that roughly 37,000 Ohioans "with severe functional loss related to extremities that prevent them from (their) major activity" needed personal care assistance. This figure gives only a general idea of that portion of Ohio's population with which this study is dealing. However, it is far from exact, and it in no way reflects the number of persons who might use a state subsidy for personal care services if one were available. That number could be much smaller; in the absence of a state subsidy program, no accurate source of that information exists.

II. Statement of Problem

According to severely physically disabled persons and to people who work with them, financial assistance with personal care services is especially needed by severely physically disabled persons who want to work and/or to live independently in order to gain control over their lives. A problem arises for those who want to work because their earnings probably would disqualify them from federally funded services that provide such care, such as Title XX programs and Medicaid, but they also could not afford to pay for the care from their wages. Many thus remain unemployed and must be dependent on family members or live in institutions in order to get the care they need. An additional problem is that persons who do qualify for the federally funded services find that those services are often controlled by the provider, i.e. the agency that administers the services, and the recipients have little control over the care that they receive.

Thus, as seen by both severely physically disabled people and persons who work with them, the problem is twofold: (1) provision of financial assistance for personal care services in order to foster employment and/or independent living and (2) control of the personal care services by a recipient in order to encourage independence. To determine if this statement accurately reflects the situation in Ohio, this study examined public and private assistance with personal care services available in Ohio as well as innovative assistance programs in other states, evaluated the assistance available in Ohio and the need in the state for additional assistance with these services, and considered alternatives for providing that assistance.

III. Report Outline

Chapter Two describes RSC activities concerning attendant care. Chapter Three discusses relevant services under the federal Title XX social services program, Chapter Four, relevant Medicaid services, and Chapter Five, social security disability insurance and Medicare. The sixth chapter is a review of other services available in Ohio. Chapter Seven presents personal care assistance programs in nine other states. Chapter Eight is an evaluation of assistance in Ohio. Finally, the last chapter discusses alternatives for an assistance program in this state.

Appendix A lists the maximum income an Ohioan is allowed for free Title XX services and for Title XX services with a fee payment. Appendix B indicates the amount of the fees that are charged for Title XX services to families of from one to six persons. Appendix C lists the Title XX services available in each county. Appendix D is a statement of need by RSC for subsidized attendant care in Ohio.

CHAPTER 2. OHIO REHABILITATION SERVICES COMMISSION ACTIVITIES

I. Introduction

The Ohio Rehabilitation Services Commission (RSC) is the state agency that is most directly involved in providing services for severely physically disabled Ohioans. It receives approximately 14% of its moneys from the state and the remainder from the federal government through the Rehabilitation Services Administration (RSA) located in the federal Department of Education. RSA and state agencies that receive funds through it are guided by the Rehabilitation Act of 1973 and its 1978 amendments.

RSC, as the federally required designated state unit, uses federal funds to administer two programs through which severely physically disabled persons may receive assistance with personal care services. Following is a discussion of the applicable federal rehabilitation statutes and RSC's activities concerning attendant care.

II. Title VII of the Federal Rehabilitation Act

Part A of Title VII of the 1978 amendments to the Rehabilitation Act of 1973 provides grants for comprehensive services for independent living, among which is attendant care. Part A has not yet been and probably will not be funded.

In 1978, in response to lobbying from disabled citizens and to the results of the 1975 Comprehensive Service Needs Study conducted by the Urban Institute for the federal Rehabilitation Services Administration, which stressed a need for independent living programs for disabled persons, Congress amended the Rehabilitation Act of 1973 by adding, among other

provisions, Title VII, Comprehensive Services for Independent Living. This statute authorizes grants to states to assist them in providing independent living services to persons who are so severely disabled that they currently do not have employment potential but who "may benefit from vocational rehabilitation services which will enable them to live and function independently." This is a marked departure from earlier rehabilitation legislation that authorized the provision of services to disabled persons only if they were working toward a vocational goal (see below).

Part A of Title VII allots annual grants, of at least \$200,000 to each state that meets specified criteria, for the purpose of funding 90% of the state's expenditures for comprehensive services for independent living. The statute stipulates what the services may include; among them is attendant care. However, Congress has not yet funded Part A, and spokespersons from both RSA and the Ohio Rehabilitation Services Commission indicated that little likelihood exists that funds will be available for Part A in the foreseeable future.

Part B of Title VII creates a competitive grants program for independent living centers (ILC's), i.e. resource facilities offering services, including assistance with personal care services, to disabled persons to help them live independently. In Ohio a specially designated Office in RSC coordinates the ILC program. Two ILC's are currently operating in Cleveland and Cincinnati.

A second component of Title VII, Part B, creates a grant program for the establishment and operation of independent living centers. An independent living center (ILC) is a resource facility that offers a number of services to disabled persons to assist them in living independently, i.e. living on their own with as much direction and control over their own lives as possible. A center that is funded under a Part B grant must assure that

disabled individuals will be substantially involved in policy direction and management of and be employed by the center and must provide a combination of the following services: intake counseling; referral and counseling concerning attendant care; attendant care and training of personnel to provide it; counseling and advocacy concerning legal and economic rights and benefits; independent living skills, counseling, and training; housing and transportation referral and assistance; surveys, directories, and other activities to identify appropriate housing, accessible transportation, and other support services; health maintenance programs; peer counseling; community group living arrangements; education and training necessary for living and participating in the community; social and recreational activities; and any other appropriate services. Federal law does not prohibit the use of these grant moneys to pay persons to provide personal care services, but an ILC projects specialist with RSA indicated that this is not a very economical use of the moneys because the grants average \$100,000 to \$200,000 annually and must be used to fund a wide range of services. Thus, in the area of personal care services, most ILC's attempt to locate and train possible attendants but do not pay them directly.

A designated state unit may apply to RSA for a grant on behalf of a public or nonprofit agency or organization that wants to operate an ILC. If RSA decides to award that particular grant, it does so to the state unit, which then contracts with the agency or organization for operation of the center and passes the grant through to the agency or organization. The ILC grants are competitive, and thus there are no minimum or maximum funds allotted to each state. The funding level for the entire program is \$18,000,000 for fiscal year 1981; it will probably remain the same for each of fiscal year 1982 and fiscal year 1983.

Prior to March 30, 1981, ILC projects could be funded on an annual basis for up to three years. On that date a new regulation took effect that provided that new projects receiving grants after that time could be funded on an annual basis for up to five years. If a project is not self-supporting by the end of the third or, for new projects, fifth year, its operating agency or organization must submit a new application if it wants to receive additional grant moneys. A project year runs from July 15 to July 14. The program does not require a state or local match by an ILC project, but a local match demonstrates local support and increases an agency's or organization's chance of receiving a federal grant.

In Ohio the Office of the Program Specialist for Independent Living and Welfare in the Division of Special Populations at RSC is the state designated unit for the ILC grants program. The Program Specialist works with groups around the state to assess the need for an independent living center in each group's area and, if such a need exists, to develop a grant proposal. His Office submits grant applications to RSA, contracts with recipients of grants, and passes the federal moneys through to them. It does not receive any state moneys for independent living centers. Currently Ohio has two ILC's that are being funded under Part B, and RSC submitted a grant application in 1981 for two new centers. RSC did not receive the grant, but it intends to reapply. Following is a brief description of each center and its existing or proposed personal care services program.

Services for Independent Living, Inc. (SIL) is located in Euclid and has been providing services to the Cleveland area since March, 1981. It is currently in its second year of federal funding (funding for the first year, which ended July 14, 1981, was used to organize the center as well as begin provision of services) and has received a grant of \$230,417, part of which is

funds not spent during the first year. The center is supplying a 5% in-kind local match, equivalent to \$12,128. One of its numerous services for disabled persons is the compilation of a registry of attendants. A full-time coordinator of attendant care development is attempting to recruit and screen persons who want to work as attendants as well as provide training, perhaps by the Red Cross or a local hospital, for those who pass the screening. Individuals who need personal care services can then contact SIL to locate and hire a screened and trained attendant. If an individual hires an attendant from the SIL registry, the center will provide follow-up including client/attendant counseling.

Cincinnati's Total Living Concepts, Inc. (TLC) opened its doors in September, 1981. It, too, is in its second year of federal funding; its first year's funding was used for organization. TLC has received a grant for \$186,809 for this second year and is providing a 12% in-kind local match of \$20,757. Because it only opened recently, it is not fully operational. Like SIL, one of its services will be to assist its disabled clients in obtaining personal care services. An attendant services coordinator will attempt to locate and screen attendants and teach clients how to interview, train, and work with attendants.

In 1981, RSC applied for, but did not receive, a \$199,640 ILC grant to be used to start two new independent living centers. Under it, \$99,640 would have gone to Wheelchair Pilots, Inc. (WPI) in Dayton, and \$100,000 would have gone to the Mid-Ohio Board for an Independent Living Environment (MOBILE) in Columbus. The services WPI planned to offer included an attendant care program that would include attendant training, matching attendants with clients, client training, and emergency attendant care. As its personal care services component, MOBILE intended to provide personal care assistance training for

clients and attendants, information/referral and a central listing of possible attendants, publicity and recruitment, and a model program that would divide the city into four areas and provide an on-call attendant in each area. RSC will reapply for the grant and, in the meantime, is exploring alternate funding sources for the centers.

III. Bureau of Vocational Rehabilitation/Bureau of Services for the Visually Impaired

The Bureau of Vocational Rehabilitation (BVR) and the Bureau of Services for the Visually Impaired (BSVI) in RSC, under federal guidance, focus on providing rehabilitation services for disabled people with vocational potential. As part of their program, BVR and BSVI pay for attendant care for approximately 150 clients annually only while they are in the program.

Prior to the 1978 amendments to the Rehabilitation Act of 1973, the federal rehabilitation program was aimed solely at providing vocational rehabilitation services for persons who had "a physical or mental disability . . . (that constituted or resulted) in a substantial handicap to employment and . . . (could) reasonably be expected to benefit in terms of employability from vocational rehabilitation services" In spite of the 1978 amendments, vocational rehabilitation remains the primary goal of the federal program, which is administered by RSA. Under Title I of the 1973 Act, RSA makes vocational rehabilitation services grants to states that have submitted to it three-year plans for providing these services to their disabled citizens. Ohio is a recipient of federal moneys for vocational rehabilitation services; RSC, through its Bureau of Vocational Rehabilitation (BVR) and Bureau of Services for the Visually Impaired (BSVI), administers the state's program.

BVR and BSVI work in tandem in implementing that program. For example, if a physically disabled person who is also visually impaired qualifies for the program, s/he will receive services through BSVI. When discussing provisions of the program or compiling statistics concerning it, RSC considers the two bureaus as a single unit. Thus, the following description of the program refers to "BVR/BSVI," a single unit.

According to a spokesperson from BVR/BSVI, a person can be accepted into the program if s/he is disabled and a "reasonable expectation" exists that s/he will benefit from employability that stems from the program's services. As one of those services, BVR/BSVI offers attendant care to clients who are going through its vocational program by paying the wages of the clients' attendants. BVR/BSVI estimates that 150 clients per year, or .2% of all persons served by RSC, receive personal care services through the program. Under that program a client selects his/her own attendant, and BVR/BSVI then negotiates with the attendant to set the attendant's fee. Because of this system of determining wages for attendants, BVR/BSVI has no firm figures on the amount it spends annually for personal care services, but it estimates that the annual cost per client is between \$1,000 and \$3,000 for an approximate total annual cost of \$300,000. This represents slightly over 1% of all case service dollars spent by RSC. BVR/BSVI also estimates that 80% of those moneys are federal and the remainder are state.

Ohio's three-year rehabilitation services plan states that one of RSC's vocational rehabilitation services is "postemployment services necessary to assist handicapped individuals to maintain suitable employment." However, RSC does not include personal care services among postemployment services. Thus, when a client meets his/her vocational objective in BVR/BSVI's program and leaves the program, s/he is not eligible to have his/her attendant paid

by BVR/BSVI. The only exception to this is if the individual acquires a job but will experience a delay in receiving his/her first paycheck; in such a case, BVR/BSVI will continue to pay for the person's attendant care for perhaps one month.

BVR/BSVI's payment for personal care services only for persons who are going through its vocational program is one limitation of its attendant care service. A second is that not all severely physically disabled people are accepted into its program and thus do not receive even the limited service that is available. RSC estimates that 35,000 Ohioans apply for its services each year and that 5% are not accepted because they are too severely disabled to be found eligible for vocational rehabilitation services. Thus, while BVR/BSVI annually provides payment for attendant care for 150 disabled Ohioans, another 1,750 disabled Ohioans receive no vocational rehabilitation services, including BVR/BSVI's payment for personal care services, because of the severity of their disability.

IV. Other Rehabilitation Programs

Demonstration programs grants, which might be used to fund a personal care services pilot project, are the only other federal rehabilitation moneys available for attendant care. Ohio has not applied for such a grant. RSC does not offer any other programs for personal care services.

Besides grants for independent living centers and vocational rehabilitation programs, the only other federal rehabilitation moneys that could be used for any kind of personal care services program are special demonstration programs grants made available under the 1978 amendments. These grants can be used for, among other purposes, the establishment of programs that "... hold promise of expanding or otherwise improving rehabilitation services to handicapped individuals (especially those with the

most severe handicaps) . . . irrespective of . . . vocational potential, who can benefit from comprehensive services" Projects can be funded for a maximum of three to five years; the amount of state or local match required is determined by the type of project. The fiscal year 1981 funding level for grants used for the above purpose is \$9,000,000, and a spokesperson for the Rehabilitation Services Administration indicated that the funding level for fiscal year 1982 may increase by \$1,000,000. The spokesperson also opined that the grants could be used to fund a personal care services pilot project. However, no one in Ohio's public or private sectors has yet applied for a special demonstration programs grant for any purpose.

V. Conclusions

The limitation of federal moneys for personal care services for severely physically disabled people to ILC programs, vocational rehabilitation programs, which stress employability, and demonstration programs is more than evident at Ohio's Rehabilitation Services Commission. RSC does not provide personal care services through any of its programs other than its embryonic ILC program, by which it channels through federal moneys that are used to locate and train, but not pay, attendants, and its limited attendant care service in BVR/BSVI.

CHAPTER 3. RELEVANT TITLE XX SERVICES IN OHIO

I. Introduction

Title XX is a federal program through which states may use federal moneys to provide social services to their citizens. As first implemented, the program was based on income eligibility. As a part of its Title XX comprehensive services program plan, Ohio now offers two services, homemaker/home health aide and chore, through which eligible recipients might receive personal care services. On October 1, 1981, the federal Omnibus Budget Reconciliation Act of 1981 became effective; it made sweeping changes in Title XX, including the elimination of income eligibility. However, because the changes are so recent, Ohio's program, as outlined in its plan, is operating under the earlier provisions.

This chapter describes both Title XX and the changes made in it by the Omnibus Act and Ohio's program in effect at the time this report was prepared. In addition, it discusses the provision of personal care services for severely physically disabled persons through Ohio's Title XX program and the possibility of increasing that provision by changing Ohio's program.

II. Overview of Federal Program

Prior to the enactment of the federal Omnibus Budget Reconciliation Act of 1981, Title XX provisions included the distribution of funds to states on a reimbursement basis, a requirement of matching funds, income eligibility criteria, a requirement that fees for services be charged under certain circumstances, and a requirement that a state have a comprehensive services

program plan. The Omnibus Act eliminated the first four provisions and changed the last to require a state to submit reports rather than plans.

Title XX was enacted in 1975 as a federal grant-in-aid program to allow states, within certain federal guidelines, to select and provide social services directed toward one or more of five goals set forth in the federal legislation. The federal Omnibus Budget Reconciliation Act of 1981, effective October 1, 1981, made major changes in the Title XX law. These changes are explained in this section, as is the Title XX law that existed prior to the Omnibus Act.

One of the changes the Omnibus Budget Reconciliation Act made was to encourage each state to adopt the goals set forth in the original Title XX legislation "as far as practicable under the conditions in that state" rather than to require their adoption as the law had done until the Omnibus Act. The three Title XX goals relevant to this study are: (1) achieving or maintaining economic self-support to prevent, reduce, or eliminate dependency; (2) achieving or maintaining self-sufficiency, including reduction or prevention of dependency; and (3) preventing or reducing inappropriate institutional care by providing for community-based care, home-based care, or other forms of less intensive care. Under these goals, a state could provide home-based personal care services through, for example, home health aide services.

From the annual federal Title XX appropriations, annual allotments are made to each state based on its population. From 1975 until the effective date of the Omnibus Budget Reconciliation Act, a state's allocation was available to it on a reimbursement basis after the state had provided services to eligible persons, and a state was required to provide 25% matching funds for all services except for family planning, which the federal government reimbursed at a 90% rate. A state's matching funds could come from public or

private sources. Since October 1, 1981, however, no state matching funds are required, and the federal funds are paid as a block grant, not on a reimbursement basis.

Prior to the enactment of the Omnibus Budget Reconciliation Act, eligibility for Title XX was based on an individual's income. The federal government required each state to provide services to all Aid to Dependent Children (ADC) and Supplemental Security Income (SSI) recipients (for a discussion of SSI, see Chapter 4) and permitted a state to provide services to any other person over the age of eighteen whose income did not exceed 115% of the state's median family income. A state could set its income eligibility limit below the 115% level for any or all services. With the exception of the provision of protective services, family planning, and information and referral services, the federal government would not reimburse a state for services the state provided to an individual or family with an income above 115% of the state's median income level, adjusted for family size. However, the Omnibus Budget Reconciliation Act eliminated all income eligibility criteria from Title XX so that, after October 1, 1981, any Title XX service may be provided to any person regardless of his/her income. A state may, of course, establish its own income eligibility limits.

Until the Omnibus Act removed all fee requirements, a state had to charge fees for services provided to an individual or a family whose monthly gross income exceeded 80% of the state's median income for a family of four, adjusted for family size, and the state could charge fees for services provided to an individual or a family whose monthly gross income was less than 80% of the state's median income, adjusted for family size. However, no ADC or SSI recipient could be charged a fee for any service provided to him/her. Federal regulations, now superseded by the Omnibus Act, required that, in a

state in which geographic subdivisions, such as counties, were responsible for providing services, each such geographic area had to provide at least three services for SSI recipients and at least one service directed toward each of the five program goals. In addition, medical and medical-related services available to an individual through Medicaid, Medicare, or an individual or group health insurance or health maintenance plan were not reimbursable through Title XX. All these requirements have been eliminated.

Until the enactment of the Omnibus Act, a state had to have a comprehensive services program plan, describing services to be provided; the geographical areas in which they would be provided; categories of recipients; planning, evaluation, and reporting activities; organizational structure; extent of the use of volunteers; coordination with Aid to Dependent Children, child welfare, Supplemental Security Income, and Medicaid services; estimated expenditures by service, category of recipients, and geographical area; and steps taken to ensure that the needs of all eligible state residents were taken into account. The services plan could be submitted every one, two, or three years, at the discretion of the state. The Omnibus Budget Reconciliation Act, however, reduced these requirements. Now, a state submits "reports," rather than "plans," and the reports do not have to include information on planning, evaluation, organizational structure, use of volunteers, coordination with other programs, and steps taken to ensure that the needs of all eligible state residents are taken into account.

III. Overview of Ohio's Program

The Department of Public Welfare administers Ohio's Title XX comprehensive services program plan, which was developed prior to the enactment of the Omnibus Budget Reconciliation Act of 1981. Services are provided through county welfare departments.

Ohio's Title XX Comprehensive Annual Services Plan for state fiscal year 1982 was developed on the basis of federal Title XX law in effect prior to the Omnibus Budget Reconciliation Act, and Ohio law requires that the provisions of the state plan continue in effect throughout the fiscal year, notwithstanding the major changes in federal Title XX law. However, this Title XX plan assumed a \$133 million federal allotment to Ohio, and, because this was subsequently reduced to \$113 million, Ohio will have to reduce the services included in its current plan or make up the \$20 million loss from other sources.

The Ohio Department of Public Welfare is the state agency responsible for administering Ohio's Title XX program, but each of the 88 county welfare departments is responsible for developing a plan of services for its county and arranging for the provision of the services, usually through contracts with other "provider" agencies. The state allots to each county a share of the state's Title XX allotment, and the county then determines what services to provide to meet its particular needs. Former Title XX law required each county to provide at least three services for SSI recipients and at least one service directed at each of the five program goals, and these requirements are included in the Ohio plan.

Ohio law requires that a portion of Ohio's Title XX allotment be paid to two other state departments, the Department of Mental Health and the Department of Mental Retardation and Developmental Disabilities, for social services these departments provide. The statutes mandate that the Department of Public Welfare enter into a contract with each of these departments to implement this required allocation of federal funds. Although the following amounts will be reduced because of the federal reduction in Title XX funds in federal fiscal year 1982, the state plan allocates federal funds as follows:

\$18.6 million to the Department of Mental Health, \$18.4 million to the Department of Mental Retardation and Developmental Disabilities, \$2.1 million for state administrative costs, \$32.5 million to county welfare departments for administration and services the departments provide directly, not through contracts with other agencies, \$20.7 million for day care for children, and \$40.8 million for services to be purchased from agencies other than county welfare departments.

Ohio has established maximum income levels for free Title XX services and for services with the payment of a fee. The state provides free Title XX services to persons whose family incomes are equal to or less than 55% of the state's median family income, adjusted for family size, and provides services for a fee to persons whose family incomes are above 55% but do not exceed 80% of the state's median family income, adjusted for family size. The maximum income levels were frozen at the median income levels of fiscal year 1980 in order to enable the state to maintain its expenditures within its federal allocation and to assure state compliance with the federal government's requirement that 50% of a state's Title XX expenditures be for persons who are eligible for ADC or SSI. This so-called "50% requirement" was eliminated by the Omnibus Budget Reconciliation Act.

IV. Personal Care Services Under Title XX

The Department of Public Welfare uses Title XX moneys to provide homemaker/home health aide and chore services, both of which can be used to assist with attendant care. Statistics on the numbers of severely physically disabled persons who use these services are unavailable. Title XX moneys are also used to support an Assistance for Independent Living Program through the Commission on Aging.

The state plan defines Title XX services and lists those that will be provided in each county (see Appendix C). From the perspective of this study, the most important of these services is homemaker/home health aide services, which could be used to provide attendant care for a severely physically disabled person, and which, according to the state plan, are available in every county except Morrow, Preble, and Shelby. Homemaker/home health aide services are defined as "professionally directed and supervised personal care and home management services provided by trained homemakers and home health aides to preserve or strengthen the functioning of individuals or families in their own homes, or to supplement such functioning in the event of illness, disability, or temporary absence of a responsible person or during periods of family or individual crisis where no other responsible person is available for this purpose."

A second service that could be provided under Title XX in conjunction with homemaker/home health aide to assist a severely physically disabled person in an independent living situation is chore services. These are defined as the "provision of help for persons unable to handle simple household tasks necessary for them to remain in their own homes or other independent living arrangements. Such tasks include running errands for food and other essentials and simple household repairs to maintain a safe environment (such as changing light bulbs in ceiling fixtures, snow and ice removal, yard maintenance, tacking loose carpet or tile, washing walls or windows, moving of furniture for periodic house cleaning, etc.)." These services do not include those of a trained homemaker or a personal care specialist. According to the state plan, 60 counties provide chore services.

According to the Department of Public Welfare, during the state's fiscal year 1980, the most recent year for which the Department has these statistics,

1,377 persons who met the SSI disabled definition received one or more units of homemaker/home health aide services through Title XX, and 127,271 units of homemaker/home health aide services were provided to persons who met the SSI definition of disabled. During this same period, 378 persons who met the SSI disabled definition received one or more units of chore services, and 24,362 units of these services were provided to SSI disabled persons. Each unit of these services represents one hour spent providing the service, making collateral contacts, or making arrangements for the service. The total cost of providing these homemaker/home health aide services was \$1,319,063; the total cost of the chore services was \$113,801. Both these cost figures include a proportionate share of state and county administrative costs calculated by the Department of Public Welfare. These data do not include services provided through the Department of Mental Health and the Department of Mental Retardation and Developmental Disabilities Title XX contracts.

The numbers cited above of persons receiving these services represent more than severely physically disabled persons because SSI's definition of disabled is broader than that being used in this study. Consequently, these data are of little help for purposes of estimating the number of severely physically disabled persons in Ohio needing or receiving personal care services. However, the staff included the data because they are the only such information available on Title XX expenditures and recipients for these services.

Ohio also uses Title XX funds to support an Assistance for Independent Living Program through the Ohio Commission on Aging for persons age 60 and over. The Commission receives a state appropriation that it allocates among its Area Agencies on Aging. These local agencies then enter into donation-of-funds agreements with county welfare departments for the provision of

independent living services, and the departments use the state moneys as the 25% match for the federal Title XX moneys that they have received for these services. The services include homemaker/home health aide and chore services as well as transportation services. The state plan permits group eligibility determination for individuals age 60 and over, which means that a county welfare department need not determine the income eligibility of each person who is age 60 or over. By virtue of being age 60 or over, a person is automatically eligible to receive these services if s/he needs them to assist in independent living and if the funds are available to provide the services to him/her.

According to the Commission, the average statewide cost of the program is \$16 an hour. The actual cost of the services provided varies among the counties, depending upon the type of agency with which the county welfare department contracts, the particular services provided, and the level of training and skill required to provide a particular service. Hourly rates range from \$1.50 to \$17 or \$18 for home health aides in some counties. During fiscal year 1981, \$1,466,341 in state funds were spent on this program, \$775,735 for homemaker/home health aide services and \$152,882 for chore services.

Finally, the state plan allows each county to establish a maximum of two groups to which to grant group eligibility for Title XX services in that county. The plan states that counties must be reasonably certain that any such group the county designates will meet the federal requirement that at least 75% of the individuals who are members of the group have gross annual family incomes of less than 90% of the state's median income, adjusted for family size. Because the Omnibus Budget Reconciliation Act eliminated income as an eligibility criterion of Title XX services, Title XX group eligibility

provisions will be unnecessary under federal law. However, the General Assembly directed that Ohio follow the current plan for the balance of fiscal year 1982, and this stipulation thus continues in force.

V. Conclusions

Under changes in Title XX resulting from the Omnibus Budget Reconciliation Act, Ohio could develop an attendant care services program for severely physically disabled persons. However, this would entail reducing funds for other services currently in existence.

As Title XX existed before the Omnibus Budget Reconciliation Act changes, homemaker/home health aide services could be provided in Ohio to a severely physically disabled person whose income did not exceed 80% of the state's median income, adjusted for family size. As explained earlier, homemaker/home health aide services would be free if the severely physically disabled person's income was 55% or less than the state's median income. This means that a single person could receive free services if his/her gross annual income was \$5,486 or less, and s/he could receive services for a fee if his/her gross annual income was \$7,982 or less. With the recent elimination of any federally mandated income limits, services may be provided for persons regardless of their income unless a state imposes income limits.

Under Title XX, Ohio has not developed an attendant care services program specifically for severely physically disabled persons as have some states although currently homemaker/home health aide services are available in all but three counties and some severely physically disabled persons in Ohio probably receive attendant care services through Title XX. However, the availability of funding for Title XX services is limited, and a severely physically disabled person must compete with other persons in need of similar services from a homemaker/home health aide agency. Whether a severely

physically disabled person receives personal care assistance services depends upon his/her income being within the limits cited above, the amount of money a county allocates for homemaker/home health aide services, and the demand for homemaker/home health care services in that county.

As Title XX presently operates, a severely physically disabled person does not control his/her attendant care services; s/he may not select and train his/her own attendant but must receive services from personnel of an agency under contract with the county welfare department.

With virtually all federal restrictions now removed from Title XX, Ohio could create a state program to provide attendant care services for severely physically disabled persons and fund it totally from federal Title XX funds unless the General Assembly imposes restrictions on Title XX that would preclude an attendant care program of this type. Assuming no such restrictions are enacted, however, one major problem remains: the scarcity of funds. Ohio has been spending all of its federal Title XX funds on its existing services program; creating a new program of attendant care services for severely physically disabled persons would require reducing funds from other services. These reductions would be in addition to those already required as a result of federal reductions in Title XX appropriations.

CHAPTER 4. RELEVANT MEDICAID SERVICES IN OHIO

I. Introduction

Some aspects of personal care services are medical in nature, and thus a discussion of Medicaid, which provides reimbursement for certain medical services provided to eligible persons, including home health care, is appropriate in this study. This chapter describes the applicable federal Medicaid requirements, Ohio's program, and the limited use of Medicaid in Ohio to provide attendant care for severely physically disabled persons. It also addresses the problems of using Medicaid for personal care services in Ohio.

II. Overview of Federal Program

In accordance with federal guidelines, states that participate in Medicaid must provide coverage to persons receiving or eligible to receive ADC or SSI and must provide specified services, including certain home health services.

Medicaid is a federal-state program authorized by Title XIX of the Social Security Act that reimburses medical providers for certain medical services provided to eligible persons. With an exception explained below, federal law requires each state that participates in Medicaid to provide coverage to the "categorically needy," that is, persons who receive or are eligible to receive Aid to Families with Dependent Children (ADC) or Supplemental Security Income (SSI). The Supplemental Security Income Program is a federally administered program of income support for the aged, blind, and disabled. It became operative in January, 1974 and replaced the former state-administered programs of aid to the aged, blind, and disabled. These

"categorically needy" must be included in a state's Medicaid plan, except that a state may use more restrictive eligibility criteria for aged, blind, and disabled persons than the federal Social Security Administration uses in SSI determinations. A state must also allow a person whose income exceeds the eligibility limits to receive Medicaid benefits if he spends a certain amount of his income on medical expenses. In addition to covering the "categorically needy," each state determines, within the limits established by the federal government, what other groups of people will be eligible for that state's Medicaid program.

Federal law requires states participating in Medicaid to provide the following: inpatient and outpatient hospital services; laboratory and x-ray services; physician services; skilled nursing facility services; certain home health services; family planning services; early and periodic screening, diagnosis, and treatment services for eligible persons under age 21; and rural health clinic services. A state must also provide transportation to and from medical providers and may provide under its Medicaid program other medical or remedial services recognized under state law. A 1981 amendment to the federal Medicaid law permitting the Secretary of the Department of Health and Human Services to allow state Medicaid programs to include "home or community-based services" is discussed in section IV of this chapter. Persons eligible for Medicaid may receive services from institutions, groups, and individuals who have signed provider agreements with the state agency that administers the program.

Federal financial participation in the cost of Medicaid benefits is based on the state's per capita income. For Ohio, the federal government pays 55% and the state pays 45%. Federal reimbursement for allowable state

administrative expenditures is generally at a 50% rate but varies according to the type of administrative expenditure.

III. Overview of Ohio's Program

Federal law makes SSI recipients eligible for Medicaid and requires the cost of attendant care to be excluded from the earned income of a recipient of SSI. This exclusion is not a part of Ohio's Medicaid program because Ohio requires a recipient of SSI to meet additional criteria in order to be eligible for Medicaid.

As required by federal law, Ohio provides Medicaid coverage to all ADC recipients. Ohio has chosen the option, however, of using eligibility criteria more restrictive than those of SSI in determining the Medicaid eligibility of SSI recipients.

Before explaining Ohio's more restrictive criteria, a brief description of federal SSI disability criteria will be useful. An individual is disabled for purposes of SSI if s/he is unable to engage in any "substantial gainful activity" by reason of any physical or mental impairment that can be expected to result in death or that has lasted or can be expected to last for a continuous period of not less than twelve months and that is demonstrable by medically acceptable techniques. The physical or mental impairment must be of such severity that the individual is not only unable to do his/her previous work but cannot, considering his/her age, education, and work experience, engage in any other kind of substantial gainful work that exists in the national economy. The Secretary for Health and Human Services must prescribe, by regulation, the criteria for deciding when services performed or earnings derived from services show an individual's ability to engage in substantial gainful activity. In 1980, the federal SSI law was amended to require that, in making the determination of whether an individual is able to engage in substantial gainful activity by reason of his/her

earnings, when the individual's disability results in a functional limitation requiring assistance in order for him/her to work, an amount equal to the cost of his/her attendant care services and certain medical devices, equipment, prostheses, and other similar items must be excluded from his/her earnings. The amount of these exclusions is subject to reasonable limits established by the Secretary.

These SSI exclusions from earned income are not a part of Ohio's Medicaid program because Ohio has chosen not to allow all SSI recipients to be automatically eligible for Medicaid. Instead, Ohio requires an SSI recipient to meet additional criteria in order to be eligible. In Ohio, a person who receives SSI or is eligible for it but does not receive it and who has independent living arrangements is eligible for Medicaid if the person's income from all sources other than SSI does not exceed \$222 a month. (This amount is adjusted annually at the same rate as is used for the federal cost of living adjustments in SSI payments.) In addition, a person who would be eligible to receive SSI except that his/her income exceeds the SSI income eligibility limit by \$222 or more may receive Medicaid benefits on a "spend-down" basis if the expenses s/he incurs for medical care in a month equal or exceed the maximum allowable monthly income cited above.

If a recipient becomes employed and his income exceeds the allowable amount, his/her Medicaid eligibility ceases. In calculating "net countable income" for Medicaid eligibility in Ohio, there are two allowable deductions: first, \$20 is deducted from income from all sources and second, \$65 plus one-half of that balance is deducted from earned income. The resulting income is compared with the Medicaid need standard, which at present is \$222 for a single person in an independent living situation. This means that a severely disabled person in an independent living situation may earn no more than \$527

a month and retain his/her Medicaid eligibility. As noted above, Ohio's Medicaid program does not provide for the exclusion from a severely disabled person's earned income of the costs of attendant care, medical devices, and other similar items as is required by federal law in states in which SSI recipients are automatically eligible for Medicaid.

Two Medicaid services could provide attendant care services to a severely physically disabled person. The first of these is home health care, and the second is personal care, an optional Medicaid service not offered in Ohio's program.

The 1967 Amendments to the Social Security Act made home health care a mandatory Medicaid service, effective July 1, 1970. Home health care services are provided to a recipient at his/her place of residence (not including a hospital, a skilled nursing facility, or an intermediate nursing facility except under special conditions) on his/her physician's orders as part of a written plan of care that the physician reviews every 60 days. Federal law requires a state Medicaid plan to provide, at a minimum, three home health care services: nursing services, home health aide service, and medical supplies, equipment, and appliances suitable for use in the home. Nursing services must be made available either on a part-time or intermittent basis by a public or private home health agency that meets requirements for participation in Medicare or by a registered nurse if there is no such agency in the area. Home health aide service must be provided by a home health agency, and, at present, the maximum payment for home health aide service is \$20 a visit.. Home health care services thus can be used to provide personal care services. They are available under Ohio's Medicaid program.

An optional Medicaid service is personal care services. These are defined by federal regulation as services prescribed by a physician in

accordance with the recipient's treatment plan and provided to the recipient in his/her home by an individual who is supervised by a registered nurse, qualified to provide the services, and not a member of the recipient's family. Ohio's Medicaid plan does not provide personal care services.

Unfortunately, there are no data available from which to determine the number of severely physically disabled persons in Ohio who currently receive attendant care services through Medicaid home health care or the costs of that care.

Medicaid data are reported by expenditures for each of the mandatory and optional services and by expenditures for each of the various categories of eligibility of Medicaid recipients, that is, expenditures for those who receive ADC or who receive SSI because they are aged, blind, or permanently and totally disabled. However, the definition of permanently and totally disabled includes not only persons with varying degrees of physical disabilities but also those persons who have mental disabilities. Moreover, there is no refinement of the data to indicate the particular types of services provided within each of the service categories. Thus there is no way of knowing the amount of attendant care services being provided through Medicaid home health care services, much less the amount of these services being provided to severely physically disabled persons. With regard to the provision of attendant care services through Medicaid, although the Department of Public Welfare does not restrict the number of reimbursable home health care visits per month for a recipient, the Department has a policy of not reimbursing home health agency services for a particular recipient if, considering all the Medicaid services the individual receives, it would be cheaper for Medicaid if the individual were to reside in a nursing home.

IV. Recent Federal Medicaid Changes

Two recent federal changes in Medicaid could affect the program's ability to provide attendant care services for severely physically disabled persons. The first is the new option of providing "home or community-based services," which might increase the availability of attendant care. However, the second, the imposition of reductions in federal Medicaid expenditures, may counteract the potentially positive effects of the first change.

As part of the federal Omnibus Budget Reconciliation Act of 1981, Medicaid law was amended to provide that the Secretary of the Department of Health and Human Services may grant a waiver to a state to allow its state Medicaid plan to include "home or community-based services" that the Secretary approves. These services would be provided pursuant to a written plan of care to individuals who, but for the provision of the services, would require the level of care provided in a skilled nursing facility or an intermediate care facility, the cost of which could be reimbursed under the state plan. Under such a waiver, a state could provide, among other services, homemaker/home health aide services, personal care services, and habilitation services.

In order for the Secretary to grant a state's waiver request, the state would have to meet certain requirements including that of providing for an evaluation of the need for such services for individuals entitled to receive skilled nursing facility or intermediate care facility services. The state would also have to provide the Secretary with assurances of cost effectiveness, that is, under the waiver, the estimated average per capita expenditure for medical assistance for these persons could not exceed the state's estimate of its average per capita expenditure for medical assistance for these persons without the waiver.

The Ohio Department of Public Welfare is presently evaluating the possibility of applying for such a waiver to the state's Medicaid program. Were a waiver granted, it could enable severely physically disabled persons who are currently in nursing homes to receive personal care services in a noninstitutional setting, assuming that alternative residential housing were available and that the home or community-based services were cost effective.

Another change enacted as part of the federal Omnibus Budget Reconciliation Act of 1981 is a reduction in federal Medicaid payments. The federal Medicaid payment to each state will be reduced by 3% in fiscal year 1982, 4% in fiscal year 1983, and 4.5% in fiscal year 1984. However, if a state can hold its Medicaid spending below 109% of its fiscal year 1981 estimated federal share of expenditures, it will receive a dollar-for-dollar offset against the reduction in federal payments. The 109% target will be indexed for inflation after fiscal year 1982. The federal reduction will also be decreased by 1% if a state has a qualified hospital review program or a high unemployment rate or if a state's third party and fraud and abuse recoveries for the previous quarter equal or exceed 1% of the state's federal share for that quarter.

Ohio does not have a qualified hospital review program, nor is Ohio's unemployment rate expected to be high enough to qualify for a reduction on that basis. However, the Department of Public Welfare anticipates that Ohio may qualify for a 1% reduction in the federal cutback based on Ohio's third party and fraud and abuse recoveries.

V. Demonstration Projects Concerning Long Term Care Services for Medicaid Recipients

State-administered demonstration projects that are testing new approaches to long term care services for Medicaid recipients are not geared to

accommodate severely physically disabled persons who need personal care services and could be adapted to do so only with major changes.

In July, 1977, the General Assembly enacted Am. S.B. 237, which authorized the establishment of demonstration projects in the state to test new approaches to long term care services for Medicaid recipients, and Am. S.B. 221, which provided supplemental state funding of community care alternatives. The Department of Public Welfare is the administrative agent for the development and administration of projects and grants authorized by Am. S.B. 237. Five demonstration projects were developed; four remain in operation. Their services are targeted to Medicaid clients residing in nursing homes that are participating in the projects and to community-based clients at risk of being placed in a nursing home.

Because attendant care is a long term care service needed by severely physically disabled persons, especially if they are to avoid institutionalization, the staff studied the projects to learn if they can be used to help provide personal care services for this group or if they could be adapted to do so. It found that, as the demonstration projects now operate, they are not really geared to accommodate severely physically disabled persons in need of attendant care for three reasons. First, a major thrust of the projects is assessing whether people in nursing homes are receiving the proper degree of care to suit their needs; following such assessments, most people remain in the nursing homes. Second, the project clients are primarily elderly persons. Third, two of the community-based settings (foster care homes and group homes) used by the projects to remove people from or prevent them from entering institutions are not designed to meet the needs of severely physically disabled people.

Ohio might be able to adapt these projects to provide attendant care for severely physically disabled people, but several major changes would need to occur. First, the state Medicaid plan would have to be amended (see above). Additional state funding would be needed to equip the community-based settings properly. Finally, administrative problems involved in "re-gearing" the existing projects to accommodate persons needing attendant care would have to be solved.

VI. Conclusions

Medicaid in Ohio is not an ideal source of funds for personal care services because it funds those services only if they are provided by home health agencies, and there are limitations with these agencies. Additionally, Medicaid eligibility is income-based, and recipients of attendant care through Medicaid lack certain elements of control over its provision.

For several reasons, Medicaid is less than an ideal vehicle for the provision of attendant care services for severely physically disabled persons. First, as long as personal care services are not included in a state's Medicaid program, attendant care services may be provided only as a home health service by a home health agency. If no such agency operates in the vicinity of the disabled person's residence, the disabled person cannot receive attendant care services through Medicaid. Moreover, the availability of a home health agency does not necessarily mean that a severely physically disabled person will be able to receive attendant care. According to a staff person in the Department of Public Welfare's Division of Medical Assistance, there is a very high demand for the services of home health agencies in Ohio, and the agencies do not normally make multiple weekly visits to provide services. If Ohio were to provide personal care services as part of its Medicaid

program, attendant care services could be provided by persons other than home health agency personnel.

Second, because Medicaid eligibility is income-based, eligibility ceases as soon as a severely physically disabled person's income exceeds the Medicaid need standard, as explained earlier. Furthermore, the Ohio Department of Public Welfare has a policy of not reimbursing home health aide services if, considering all the Medicaid services an individual receives, it would be less expensive for Medicaid if that individual lived in a nursing home. This policy is understandable from a Medicaid standpoint of reducing costs, but it restricts the availability of home health aide services, and it may not serve the psychological needs of a severely physically disabled person.

Even if a severely physically disabled person is receiving attendant care services through Medicaid, s/he lacks certain elements of control over the provision of the services. Although the severely physically disabled person is able to choose his/her service provider, s/he is limited to those providers who have entered into provider agreements with the Ohio Department of Public Welfare. Moreover, Medicaid home health services must be part of a physician's written plan of care for an individual so that the services are directed by someone other than the recipient. In addition, the recipient does not control the service payment; the service provider is paid directly by the Department of Public Welfare.

CHAPTER 5. SOCIAL SECURITY DISABILITY INSURANCE AND MEDICARE

I. Introduction

Persons who qualify for social security disability insurance (SSDI) and have been receiving benefits under it for at least two years are eligible to receive Medicare. Because Medicare provides home health services in accordance with federal guidelines, this chapter offers a brief look at both SSDI eligibility and the applicable Medicare benefits available to an SSDI recipient.

II. Social Security Disability Insurance

Social security disability insurance provides monthly cash benefits to insured workers who meet eligibility requirements concerning length of previous employment, severity of disability, and inability to work. However, the 1980 Disability Amendments to the Social Security Act permit disabled people who return to work to deduct from their earned income the costs of personal attendant care and other devices and services necessary to enable them to work when determining whether their income causes them to become ineligible for SSDI.

In 1956, disability insurance was added to the social security system. It provides monthly cash benefits to eligible workers who are totally disabled. Like regular social security benefits, disability benefits are based on workers' average monthly earnings in insured employment (i.e. employment in which social security taxes are deducted).

Not all disabled persons are eligible to receive social security disability benefits. Three categories of disabled people are eligible if

they meet the definitions of "insured workers" and "disability" and do not engage in substantial gainful activity (see below). The first of these is insured workers under age 65 who become totally disabled for a period of one year or more. The spouse of a worker receiving benefits is also eligible for a spouse's benefit if the spouse cares for a child under age eighteen, is disabled, or is at least age 62. In addition, unmarried children of a disabled worker are eligible for dependent's benefits up to age eighteen and up to age 22 if they are in school. The second category is disabled widows, widowers, or divorced wives aged 50 to 59 who meet other requirements for widow's or widower's benefits, and the third is disabled sons or daughters of a worker entitled to disability or retirement benefits. To qualify for the last category, the son or daughter must have become disabled before reaching age 22. These childhood disability benefits are payable as early as age eighteen. Like old age and survivors' benefits in the social security system, persons who apply for disability insurance through the social security system must have worked in employment in which social security taxes were deducted for a stipulated length of time as prescribed by federal regulations.

The definition of disability governing social security disability insurance is the same as that establishing SSI disability eligibility (see Chapter 4). In the case of persons with whom this study is concerned, their disabilities are so severe that there would probably not be any doubt that they would meet the definition of disabled. However, their SSDI eligibility may vanish if they engage in substantial gainful activity (SGA). SGA is defined in federal regulations as "work activity that involves doing significant physical or mental activities. (W)ork may be substantial even if it is done on a part-time basis or if (the person does) less, gets paid less, or

has less responsibility than when he worked before." Workers who have earned more than \$300 a month in any year after 1979 are judged to have engaged in substantial gainful activity. Thus, disabled workers who are otherwise qualified to receive social security disability benefits are disqualified if they earn more than \$300 a month.

The Social Security Disability Amendments of 1980 made some changes in SSDI requirements that benefit severely disabled persons who wish to work. Under the 1980 amendments, SSDI recipients who work may deduct the costs of attendant care services, medical devices, prostheses, and similar items and services that are needed for recipients to be able to work from their earned income when determining whether the above \$300 limit has been exceeded.

Present federal law permits recipients of SSDI to engage in a trial work period of 24 months as long as they do not medically recover. The trial work period is designed to allow the persons to learn if they are able to return to work without the threat of an automatic loss of their benefits. During the first twelve months of the trial work period, participants receive both SSDI cash benefits and Medicare benefits (see below). During the second twelve months, they do not receive SSDI cash benefits, but they retain SSDI eligibility. They also retain Medicare benefits, and, if they continue to work after the 24-month trial work period, they retain Medicare benefits for an additional 24 months. Thus, recipients who begin a trial work period are entitled to 48 months of Medicare coverage from the time they begin the trial work period. If an individual fails in a trial work period because his/her income dips below SGA or s/he is simply unable to continue working, s/he returns to regular SSDI status and receives both SSDI cash benefits and Medicare benefits.

III. Applicable Services Available Under Medicare

Medicare is a national health insurance program available to recipients of SSDI, among others, without regard to income. It provides coverage for home health care visits if the recipient needs part-time or intermittent skilled care, is homebound, and has the services prescribed by a physician.

Medicare is a national health insurance program available without regard to income to persons who are at least 65 years old, persons eligible for SSDI, and certain workers or their dependents who need kidney transplants or dialysis. It consists of two parts. Part A is insurance for hospital costs, care in skilled nursing facilities, and home health care. Further requirements concerning home health care are that the recipient must be in need of part-time or intermittent skilled nursing service or physical or speech therapy, have had the service prescribed by a physician, and be homebound. If a person meets these requirements, s/he may receive assistance with "simple procedures" in addition to the skilled care (i.e. skilled nursing service or therapy). This assistance consists of personal care services as well as certain household services that do not materially increase the amount of time required for the visit if they are necessary to prevent reinstitutionalization. It is provided by home health aides under the supervision of a registered nurse. A Medicare recipient usually does not receive this assistance on a daily basis. Home health care must be provided by a home health agency that participates in the Medicare program.

The Omnibus Budget Reconciliation Act, effective July 1, 1981, removed some previous limitations on home health services. There is no longer a requirement that a recipient must have been in a hospital for at least three days prior to receiving services or that a recipient may only receive 100 visits per year.

Part B of Medicare is a voluntary program paid for in part by the participants. As a result of the Omnibus Budget Reconciliation Act, its features and requirements are nearly identical to those of Part A. The major difference is that a payment cannot be made under Part B if the participant is eligible for a similar payment under Part A.

IV. Data

No specific data exist on the numbers of severely physically disabled persons who are receiving personal care services through Medicare.

As of June 1980, the most recent date for which statistics are available, 132,036 persons in Ohio were annually receiving social security disability benefits according to the Rehabilitation Services Commission. The federal Health Care Financing Administration reported that, as of January 1, 1980, 139,838 SSDI recipients in Ohio were insured under Part A Medicare per year, and 128,319 SSDI recipients were insured under Part B Medicare. These figures include persons with other types of disabilities, and the staff is unable to project what percentage of SSDI or SSDI-Medicare recipients are severely physically disabled or what percentage are severely physically disabled and receiving personal care services through Medicare.

V. Conclusions

Medicare is probably not a viable source of funding for personal care attendants for severely physically disabled persons because Medicare's restrictions require that skilled care be needed and that the recipient be homebound. Personal care services are not covered unless they are accompanied by the provision of skilled care. Not all severely physically disabled persons require skilled care, nor are all of them homebound. Additionally, in order to qualify for Medicare, a severely physically disabled person must either be 65 years old or have been receiving SSDI for at least two years. The latter

requirement means that the recipient must have been a member of the work force. Again, not all severely physically disabled persons were working prior to the time they developed a need for personal care services.

CHAPTER 6. OTHER SERVICES IN OHIO

I. Introduction

In order to present as complete a picture as possible of the provision of personal care services to severely physically disabled people in Ohio, the staff looked at the resources offered by public and private entities that provide various kinds of assistance to or work with the study's subject group. The staff learned that few financial sources exist beyond those discussed in Chapters 2, 3, 4, and 5. The staff also learned about the availability of other types of assistance concerning personal care services, such as locating attendants. Information on that topic is included in this chapter.

II. Federally Funded Services

Limited federal assistance for personal care services is available from the Veterans Administration through an allowance for aid and attendants, from the Department of Housing and Urban Development through subsidized housing, and from ACTION through programs using senior citizens to provide care.

Additional moneys for personal care services are available on a limited basis from three other federal sources. Chief among these is the Veterans Administration (VA), which provides an allowance for aid and attendants to an eligible veteran who needs that assistance because of a service or nonservice connected injury. The VA determines eligibility by evaluating the person's disability and other income; additionally, the veteran must show his/her need for funds specifically for this purpose. The maximum annual allowance for aid and attendants is \$2,700. A recipient is responsible for hiring his/her own attendant. The staff attempted to obtain more specific information on

this service from the Veterans Administration, including statistics concerning the number of severely physically disabled Ohioans who are receiving an allowance and the total annual cost of providing it for them, but the VA did not respond to the staff's request.

An apparently small number of severely physically disabled Ohioans may receive subsidized personal care services indirectly if they live in housing units constructed for handicapped persons with assistance from the Department of Housing and Urban Development (HUD). HUD aids in the construction of housing units for elderly and handicapped persons by making insured loans for their construction or insuring their mortgage. It also provides a rent subsidy for the residents of such units. Under it a resident does not have to pay more than 25% of his/her income for rent, and HUD will pay the difference, if any. Because some apartment complexes composed of HUD units provide a 24-hour attendant who is paid through each complex's operating budget, which in turn is established in part through HUD-subsidized rent, HUD is indirectly paying for this type of attendant care.

An example of this housing is the Center for Creative Living in Columbus. Creative Living is an apartment complex composed of 18 units that are specially designed for severely physically disabled persons. An attendant is on call 24 hours a day; however, the residents also hire their own attendants because the on-call attendant cannot meet all of their needs. Creative Living is located near Ohio State University and thus has a strong support system of persons to work as attendants and of other services from the university and the rehabilitation center located there (see below). In this sense it is unique in the state. Other HUD-supported housing units for handicapped persons exist in the state, but HUD was unable to provide the staff with an estimate of their number. It did indicate that in Columbus HUD has

constructed 400 units for elderly and handicapped persons; of those, approximately 50 are designed specifically for handicapped persons. Not all handicapped units are part of a complex whose operating budget provides for a 24-hour attendant.

ACTION operates two programs that provide limited attendant care among their services. Under the Senior Companion Program, which is located in the Columbus, Cleveland, and Marietta areas of the state, persons who are at least 60 years of age and who meet income eligibility are hired for \$2.00 an hour to provide assistance and light housekeeping for persons who are also at least 60 years old, frail, and homebound. The program serves 480 people at an annual cost of \$650,000. The Retired Senior Volunteer Program (RSVP) operates 31 local programs in Ohio through which retired senior citizens provide voluntary services needed in their area. Not all of the programs offer attendant care as a service. Those that do are currently providing it to 50 disabled persons.

The only other possible source of federal assistance for personal care services is community action agencies, which receive a portion of their funding under the Community Services Block Grant Act of 1981. However, in a spot check of the state's 48 agencies, the staff learned that, while some agencies do provide some services for handicapped persons, their only activity with regard to attendant care is referral, and not all provide it.

III. Other State Services

The Bureau of Workers' Compensation pays for personal care services for persons injured on the job if their need is verified by a physician. Ohio's state universities provide varying degrees of help in locating attendants for severely physically disabled students; the Ohio Rehabilitation Center at Ohio State University helps locate and train attendants for patients who are leaving.

As noted in earlier chapters, the Rehabilitation Services Commission, Department of Public Welfare, and Commission on Aging are involved in the provision of personal care services for some of Ohio's severely physically disabled persons. The only other state agency so involved is the Bureau of Workers' Compensation, which is funded through payments made by Ohio's employers. If an Ohioan becomes severely physically disabled as a result of an industrial accident and needs attendant care, s/he may request the Bureau to pay for nursing services rendered by a nonprofessional. The request must be verified by a physician and approved by the Rehabilitation Division of the Industrial Commission. If the person's request is approved, s/he must select his/her own attendant and may select his/her spouse to serve in that capacity. In 1981, a spouse serving as an attendant could receive between \$8 and \$30 per day. No other statistics concerning the Bureau's payment for nonprofessional nursing services were available from the Bureau when the staff prepared this report.

Since 1978, the General Assembly has funded an Arthritis Care Education Program (ACE) by appropriating over \$200,000 annually to the Department of Health, which passes the appropriation on to the Arthritis Foundation. Under the home care assessment aspect of the program, an occupational therapist will determine if personal care services, among others, are needed by an arthritis patient living at home. If a need exists, the ACE program will attempt to locate a source of care for the person, but it does not subsidize the care.

Ohio's twelve state universities do not subsidize attendant care for those severely physically disabled students who need it, but slightly more than half of the universities do provide other assistance with personal care services. Wright State University's Office of Student Services advertises

for attendants and puts successful applicants on its payroll. An attendant must turn in the hours s/he has worked for a disabled student to the Office, which in turn bills the attendant's employer (i.e. the student). The employer verifies the hours and pays the Office, and the Office pays the attendant. The Office also supervises the attendants and gives seminars on relevant topics. Wright State has approximately eighteen students who receive assistance with personal care services in the 1981-82 school year. The Office of Services for Handicapped Students at Kent State University operates an active Attendant Referral Program. It advertises for and screens attendants, maintains a referral list, and educates physically disabled students concerning how to be employers. Approximately 30 Kent students are receiving personal care services with the Office's aid in the 1981-82 school year. Of the other state universities, three help locate an attendant if a student needs one, one maintains a list of possible attendants, and one has no specific program but helps with personal care services on an individualized basis.

The twelve state universities currently have fewer than 100 severely physically disabled students who need personal care services. Persons at the universities who work with the students indicated to the staff that one of the reasons for this small number is an inability to pay for attendant care that will enable the students to leave home and attend school. Although the Bureau of Vocational Rehabilitation/Bureau of Services for the Visually Impaired in the Rehabilitation Services Commission will pay for attendant care while a severely physically disabled person attends school (see Chapter 2), it requires the person to carry at least twelve quarter hours per term and maintain a scholastic average of at least 2.5. These requirements sometimes prove to be prohibitively stringent.

Sections 3335.50 through 3335.55 of the Revised Code establish the Ohio Rehabilitation Center at Ohio State University. The Center, located in and commonly referred to as Dodd Hall, is a part of University Hospital and has as one of its statutory requirements the rehabilitation of "handicapped or disabled persons whose rehabilitation requires extended residential care or intensive study and services" While a patient is in residence at Dodd Hall, the nursing staff provides his/her personal care services. When the patient is ready to leave, Dodd's social service component attempts to find him/her an attendant; if one is found, the nursing staff will help train the person. Dodd Hall maintains a list of possible attendants that it uses to help locate attendants for its discharged patients and that it shares with the Center for Creative Living (see above). However, a patient's attendant frequently is a member of his/her family. Locating and training attendants constitute Dodd Hall's activities with regard to personal care services for persons who are leaving the facility.

IV. Other Services

Local governments do not provide funds for personal care services. The only applicable assistance from Ohio's hospitals that have rehabilitation in-patient units is referral and occasional training of attendants. No consumer groups provide funding, and only a few help locate attendants. No insurance companies in Ohio will pay for personal care services rendered by nonmedical persons.

Publicly offered personal care services for severely physically disabled people that are funded solely through local public sources apparently are not available in Ohio. This was determined through staff contact with the county departments of welfare of Summit, Lucas, Hamilton, and Montgomery Counties; the Governor's Committee on Employment of the Handicapped in the Rehabilitation

Services Commission; the Columbus Office of the Handicapped; the Federation for Community Planning of Cuyahoga County (contacted through the Northeast Ohio Epilepsy Foundation); Cincinnati General Hospital; the County Commissioners Association of Ohio; the Ohio Municipal League; and the Montgomery County Human Relations Council. Each of those contacted stated that some local services are available in their areas of the state but that funding for them comes from a combination of federal, state, and local sources. Those contacted believed the local money comes from nongovernmental agencies, such as Easter Seals, or takes the form of paying administrative expenses and not the actual cost of the services themselves.

In addition to Dodd Hall at OSU's University Hospital (see above), fourteen other hospitals in Ohio have rehabilitation inpatient units. The staff contacted these hospitals to ascertain what they are doing concerning attendant care for patients who are leaving their rehabilitation units. Nine of the fourteen help locate attendants or, alternately, provide referral service. Three of them train attendants hired by or family members of the patients, and two others train only family members. Two hospitals "work with" a patient's family members, presumably to aid in adjustment, but they do not provide training for personal care services. The hospitals obviously are not a source of funding for attendant care.

The staff also contacted six consumer groups, in addition to the Arthritis Foundation (see above), to learn if any of their activities include help with personal care services. Two of them indicated that they attempt to locate attendants when requested to do so. None of them provide any financial assistance for attendant care.

Finally, the staff contacted the Life, Accident, and Health Division of the Ohio Department of Insurance to inquire if any insurance companies in

Ohio pay for personal care services that are provided by nonmedical persons. The head of the Division indicated that he knows of no companies that offer such coverage.

V. Conclusions

If a severely physically disabled Ohioan is a veteran, lives in HUD-assisted housing, or was injured on the job, s/he may receive financial assistance for personal care services. However, if s/he does not fit into one of these categories or is not receiving aid under any of the programs discussed in Chapters 2, 3, 4, or 5, the only help s/he would probably receive for personal care services is assistance in locating and perhaps training an attendant. Even that assistance is not always available.

CHAPTER 7. PROGRAMS IN OTHER STATES

I. Introduction

This chapter discusses nine other states that use federal moneys, state moneys, or a combination of them to provide assistance with personal care services. The staff selected the states because of their use of federal funds or their varying methods of operating state-funded programs. Massachusetts has two programs, one of which uses Medicaid moneys. California and one of Alabama's programs use Title XX funds. Massachusetts, Maine, Alabama, Vermont, Washington, Rhode Island, Connecticut, and Illinois all have state-funded attendant care programs.

II. Massachusetts

Massachusetts has two programs of attendant care services for severely physically disabled persons. One is funded by state moneys and provides attendant care services for employed severely physically disabled persons. The second is funded through Medicaid and provides attendant care services for nonemployed severely physically disabled persons and those on a trial work period. The first program has 61 participants and the second, 240 participants.

MRC-PCA Program

The Massachusetts state-funded personal care program, called the Massachusetts Rehabilitation Commission-Personal Care Attendant program or the MRC-PCA program, is administered by the Massachusetts Rehabilitation Commission. It is designed to assist severely physically disabled persons who become employed and thus lose Medicaid eligibility or eligibility for

assistance with personal care services from other sources. The intent of this participant-directed program is to enable severely physically disabled persons to enter or maintain employment by providing them with attendant care services.

An individual is eligible for the MRC-PCA program if s/he has a severe physical handicap, is receiving or has received vocational rehabilitation services from the Massachusetts Rehabilitation Commission, is employed or ready for employment, is not eligible for assistance with personal care services through any other program, and has a documented need for not less than fourteen nor more than 40 hours a week of personal care services, excluding the services of a night attendant.

A severely physically disabled person makes his/her initial application at a local MRC office, and the MRC office refers the applicant to a personal care attendant vendor for an evaluation of his/her attendant care needs by a registered nurse and an occupational therapist. The cost of this evaluation is approximately \$60. In addition to performing these evaluations, personal care attendant vendors serve several other functions in the MRC-PCA program, including being a fiscal conduit for the payments to attendants. To serve as a personal care attendant vendor in the Massachusetts program, an agency must be a nonprofit corporation with previous experience in personal care services or equivalent experience in working with severely physically disabled persons. The agency must also be able directly, or through contract, to assess an applicant's need for personal care attendant services, orient severely physically disabled persons in the supervision of a personal care attendant and in the filling out of time sheets, recruit, train, and maintain a pool of personal care attendants, prepare invoices from time sheet summaries and transfer moneys from the MRC to severely physically disabled program

participants to pay their attendants, and respond promptly to problems that program participants report. At present, the MRC-PCA utilizes four such vendor agencies.

Within ten days after receiving the vendor's evaluation of the applicant, the MRC determines the applicant's eligibility for the program. The Director of the MRC-PCA program reviews all applications and makes the final decision on each applicant. Once a severely physically disabled person is determined to be eligible, the MRC determines his/her financial need using a formula described below. The formula was adopted in 1978 and was modeled generally on the Medicaid "spend-down" formula. According to a program spokesperson, the formula is somewhat arbitrary and it favors single persons who pay more of their income in taxes. The spokesperson indicated that he is in the process of developing a new formula for the Massachusetts program to try to allow for the extraordinary expenses incurred by the severely physically disabled persons.

The existing formula operates in the following manner. First, \$1,260 is subtracted from the severely physically disabled person's after-tax annual income. Then one-half of the remaining amount is subtracted, and that balance is reduced by \$3,504. The amount remaining after these calculations is the amount the severely physically disabled person must contribute toward the cost of his/her personal care attendant services.

The MRC-PCA program is participant directed. This means that the severely physically disabled person is responsible for selecting, training, supervising, and paying his/her attendant, preparing time sheets for the hours his/her personal care attendant works and sending them to the vendor center every two weeks, and notifying his/her MRC-PCA counselor of any

changes in the participant's need for personal care services or in his/her financial status.

The severely physically disabled person selects his/her own attendant or attendants and his/her night attendant if needed, but the MRC-PCA program will not pay an attendant who is related by blood or marriage and who resides in the same residence as the severely physically disabled person. According to the program spokesperson, most of the severely physically disabled program participants live in residential facilities in the community, not in specially designed residential independent living centers.

The MRC-PCA program presently has 61 participants, of whom between 75% and 80% are quadriplegics. In its first year, the program had 30 participants. Ten were added in the second year, and 20 more during the third year. The spokesperson estimated an increase of approximately 20 more participants in the program's next year. The average cost per participant is \$7,200 a year, and the average number of hours of personal care services per participant is 32 a week. The program's appropriation for 1981 is \$575,000. The program pays an attendant \$4.25 an hour and pays \$6.07 a night for a night attendant. In addition to providing personal care services to employed severely physically disabled persons, the MRC-PCA program provides each participant with Medicaid coverage that is 100% state financed. The purpose of this coverage is to fill in any gaps in an employed severely physically disabled person's health coverage.

Medicaid Independent Living Program

Massachusetts' Medicaid Independent Living Program for severely physically disabled persons is intended to prevent such persons from being institutionalized and to foster their deinstitutionalization. The Independent Living Program is designed for severely physically disabled persons who are

fully aware of their own health needs and are able to direct and supervise their own care by an attendant or attendants selected by the disabled person. Personal care services are an optional Medicaid service defined in federal Medicaid regulations, which limit the personal care attendant provider to a nonfamily member. In addition, as with any Medicaid service, the personal care services must be prescribed by a physician in conjunction with a plan of care for the individual and must be supervised by a registered nurse.

To be eligible for this Independent Living Program's personal care services, an applicant must be at least eighteen years of age, require the use of a wheelchair to carry out routine daily living activities, demonstrate the ability and skills to manage a personal care attendant, be medically and emotionally stable, and require at least fourteen hours a week of assistance in the functions of daily living. A majority of his/her attendant's time must be devoted to the disabled person's health care and physical needs.

If the evaluation team, composed of a registered nurse and an occupational therapist, determines that an applicant meets all the criteria except that of having specific personal care attendant management skills, the applicant is eligible for skills training, reimbursable under Medicaid. This training is provided through one of the four independent living centers that are utilized as vendors in the MRC-PCA program described above; these non-profit centers serve basically the same functions in this Independent Living Program as they do for the MRC-PCA program, including performing applicant evaluations.

After determining that an applicant is eligible for the program, the evaluation team determines the number of hours of attendant care the applicant needs. The evaluation is then sent to the applicant's physician for

approval and then on for Medicaid authorization. Each participant must be reevaluated annually.

A severely physically disabled person selects his/her attendant and forwards biweekly or monthly time sheets to the independent living center serving as a vendor for the program. The vendor then submits a claim to Medicaid, the Medicaid reimbursement is sent to the vendor, and that agency forwards it to the severely physically disabled person, who pays his/her personal care attendant or attendants.

There are 240 severely physically disabled persons participating in this program; on the average, the participants use 30 hours of personal care services a week. The personal care attendants are paid \$4.25 an hour, and night attendants are paid \$6.11 a night.

III. California

California uses Title XX moneys to provide personal care services through its In-Home Support Services program. In 1980, 12,685 severely impaired persons received services through that program.

California has a program of In-Home Support Services (IHSS) that provides attendant care services for aged, blind, and disabled persons that is funded through Title XX. An individual is eligible for the IHSS program if s/he is a California resident who is a United States citizen or a lawfully admitted alien; resides in his/her own home or in a dwelling of his/her choosing that is not an institution; is eligible for or receiving Supplemental Security Income (SSI) benefits, meets all the SSI eligibility criteria except that his/her income exceeds the amount allowed, or has been eligible for SSI in the past and continues to suffer from the impairments that made him/her eligible for SSI but is now engaged in a substantial gainful activity

and is earning income in excess of that allowed under SSI; and requires IHSS care and his/her income is not sufficient to pay for his/her care.

The California Department of Social Services supervises the IHSS program, and county departments of social services administer the program at the local level. They determine an individual's eligibility, prepare a needs assessment of each applicant, and, if requested, assist a disabled program participant in finding an attendant.

Under the IHSS program, a participant may hire and train his/her own attendant who may be a relative. A severely impaired participant, defined as a person needing 20 or more hours of services a week, has the option of receiving monthly payments from the county social services department and using these to pay his/her attendant directly. Attendants are paid the minimum hourly wage.

If a participant's monthly income exceeds the amount of his/her SSI payment plus the state's supplemental payment to each SSI recipient, an amount that is \$439 for a single individual, s/he must pay all of his/her income in excess of \$439 toward the costs of his/her attendant care services. If his/her monthly income exceeds the monthly cost of his/her attendant care services, s/he is no longer eligible for the IHSS program.

In 1980, there were 97,000 persons receiving in-home support services through the IHSS program; the average cost per participant was \$215 a month. Of the 97,000 persons receiving services, 31,811 were disabled, either mentally or physically, and 12,685 of those were severely impaired as defined above. Of the total number of severely impaired persons, 2,342 were employed or in school or training programs. The maximum amount the program would pay for a severely impaired individual was \$838 a month, and the maximum amount the program would pay for any other nonseverely impaired participant was \$581

a month. Both of these figures include the state's and the participant's shares of the costs of the in-home supportive services.

IV. Alabama

Alabama helps provide personal care services through three programs. Its Homebound Program uses state subsidies to pay for attendant care for persons who have no other source of assistance. Currently it spends between \$63,400 and \$68,600 per month for 238 persons. The state also pays \$60 per month for attendant care to over 16,000 clients as aid to disabled. Alabama is also using Title XX moneys to hire ADC recipients to provide personal care services as home care aides to eligible disabled persons. Ninety persons are currently receiving such care at an average monthly savings of \$800 for each of the 25 home care aides.

Alabama provides assistance for personal care services through three programs. The first is its Homebound Program, which has been operated by the Division of Rehabilitation and Crippled Children Service in the Department of Education since 1975. State-subsidized attendant care is only one aspect of this program. To be eligible for it, a severely physically disabled person must be under 65 years of age, be homebound, not have sufficient income or resources to meet the cost of the services needed, have no other program available to him/her to provide personal care services, and be under the care of a family member who is a potential wage earner and who would be relieved to engage in outside employment if the applicant receives subsidized attendant care. Employed severely physically disabled persons usually do not receive personal care services subsidies under the Homebound Program.

A home health team evaluates each applicant and determines how many hours of personal care services, if any, s/he needs. The Homebound Program will subsidize up to 40 hours of care each week for each participant; a

spokesperson estimated that the average number of hours subsidized per day per participant is four. The participant must select his/her own attendant who must be approved by the participant's family and the home health team. An attendant can receive training either at one of the Division's centers, which are located in urban areas around the state, or from the nurse member of the home health team. The program pays \$3.35 per hour, and the Division withholds only unemployment compensation from an attendant's pay and sends checks for the remaining amount directly to the attendant who is considered to be self-employed and thus is responsible for paying his/her own taxes. Out of approximately 1,297 persons who are receiving some sort of service under the Homebound Program, 238 are receiving attendant care at a monthly cost to the state of \$63,400 to \$68,600.

According to the program spokesperson, some attendants do not understand that they must pay their own taxes even though they signed forms when they were hired indicating that they understood the tax system. They thus owe rather large sums of money at the end of each year, and this creates financial difficulty for them. The only other problem noted by the spokesperson is that the age limit prevents some persons who are over 65 from receiving personal care services.

A second Alabama program is provided through the Department of Pensions and Security. Prior to the implementation of SSI (see Chapter 4), the Department paid a monthly aid-to-disabled stipend to disabled persons for personal care services. As required by federal law, it is continuing this public assistance program and is currently paying up to \$60 a month in state moneys to over 16,000 clients.

The third program has been in existence only one year and is also administered by the Department of Pensions and Security. Under it the

Department uses Title XX moneys to hire Aid to Dependent Children (ADC) recipients to serve as personal care attendants for severely physically disabled persons who meet income criteria, which approximate Medicaid eligibility, and Title XX eligibility. The disabled person must also be "nursing home material," i.e. unable to work, but be able to live at home with assistance. The provision of personal care services must be part of an overall service plan for the person. The program is designed to provide employment for ADC recipients, help disabled persons leave or stay out of nursing homes, and enable family members of disabled persons to work.

County departments of pensions and security operate the program and are responsible for determining if home care services are appropriate for an applicant, hiring and training the home care aides who provide the services, assigning an aide to a client, and supervising the aide. Currently only six of Alabama's 67 counties have the program. Twenty-five aides are providing care for 90 participants for an average of 3.35 clients per aide. The most hours of care that are provided for a client are seventeen per week; the average ranges from eight to twelve. The Department, through the county departments, expends for each employee \$937.37 per month. This figure includes wages, social security, insurance, travel, a home care supply kit, and food stamps benefits. The program was originally funded under the Comprehensive Employment and Training Act (CETA), but, because of a reduction of CETA funds, Title XX moneys have been used since October 1, 1981.

In a cost analysis of the program, the Department compared the amount of public moneys spent to maintain both a family on ADC and a disabled person in a nursing home with the amount spent to hire a person as a home care aide. It calculated that the net savings of public moneys per month per aide is slightly more than \$800. It also noted in the analysis that, through the

program, ADC recipients have demonstrated their employability and disabled persons have been able to remain out of nursing homes. A program spokesperson could think of no problems or difficulties with the program.

V. Maine

Maine's personal care assistance pilot program is almost identical to Massachusetts' state-funded program; it received a \$145,000 two-year state appropriation. It is cost effective and will probably be continued.

Maine's state-funded personal care assistance two-year pilot program in the Bureau of Rehabilitation in its Department of Human Services is nearly identical to Massachusetts' MRC-PCA participant-directed program. The program had a \$55,000 appropriation for its first year and has \$90,000 for its second year; it has twelve participants in 1981. The average number of hours of care per participant per day ranges from four to six. Wages for an attendant are \$4.00 per hour, but a spokesperson for the program informed the staff that they may increase to \$4.25 or \$4.50 per hour in order to get "quality help."

The program spokesperson noted that maintaining a pool of attendants to provide permanent help is a problem and that, at the start of the program, liability was an issue. However, the Bureau decided that the recipient and not the state is an attendant's employer, and it thus relieved the state of liability. In spite of these problems, the spokesperson stated that the program is a success, it is cost effective, and its administrators will experience little difficulty in convincing the state legislature to continue it.

VI. Vermont

Vermont currently subsidizes personal care services for 30 to 35 employed or employable severely physically disabled persons at a monthly cost

to the state ranging from \$125 to \$675 per person. The subsidy program is a pilot program, but its success indicates that it might become permanent.

On July 1, 1980, Vermont began a pilot program in the Division of Vocational Rehabilitation in its Department of Social and Rehabilitation Services to provide state moneys to subsidize attendant care for severely physically disabled persons. An applicant to the program must be at least eighteen years old, be able to manage an attendant, be employed or enabled by the program to become employed (i.e. work for at least 20 hours per week for remuneration) or experience deterioration in employability in the absence of attendant care, have a current medical evaluation, and be approved by a three-person selection committee that includes at least one severely physically disabled person who uses an attendant.

Once accepted into the program, a participant must select and train his/her own attendant although the Division will assist the participant in learning how to be an employer. The participant, and not the Division, is considered the attendant's employer and thus must obtain an employer identification number for tax purposes, do the necessary paperwork for social security and worker's compensation withholding, and pay the attendant after receiving a biweekly check from the Division for the verified number of hours worked by the attendant.

The program's specifications stipulate that the state will subsidize fourteen to 42 hours of attendant care per person per week; however, the Division has lowered the minimum to seven hours per week for a few participants to learn if that amount of care is beneficial to anyone. The state pays \$3.80 per hour for personal care services. This amount was calculated to enable social security and worker's compensation to be withheld and still provide attendants with minimum wage take-home pay. Currently between 30 and

35 severely physically disabled people participate in the program with a monthly cost to the state ranging from \$125 to \$675 per participant. The program received a \$75,000 state appropriation for its first year of operation and a \$125,000 state appropriation for its second year; 5% of the moneys go toward administrative costs.

A spokesperson for the program indicated to the staff that the Division has no hard data on savings of public moneys resulting from the program but that the program has kept some people out of institutions. Other benefits of the program that he discussed include assistance in career development for both the participants and their family members by enabling the former to enter and the latter to return to the job market, and alleviation of tension in families by providing outside care for disabled members. Additionally, Vermont allows a participant to hire a family member as his/her attendant, and thus a family member who stays home to provide personal care services will be able to accumulate social security benefits for the future. The only problems noted by the spokesperson are "paperwork headaches," which he stated can be ironed out at the beginning of a program, and difficulty in calculating the social security and worker's compensation matches. Overall, the Division believes that the program is quite successful and hopes that the legislature will make it permanent.

VII. Washington

Washington subsidizes attendant care for disabled employed adults if, among other criteria, their earned income after subtracting work and medical expenses and the cost of chore services is less than 40% of the state median income.

The state of Washington has a program of attendant care services for disabled employed adults that is administered by the Department of Social and

Health Services. To be eligible for the program, an applicant must (1) be a resident of Washington and be eighteen years of age; (2) be employed; (3) not be a recipient of SSI or state supplementation benefits; (4) have been determined to be disabled for the purpose of receiving social security disability insurance (SSDI), Supplemental Security Income (SSI), or Washington's Medical Care Only program and have experienced no appreciable improvement in the disabling condition since the disability determination was made, or be determined by the Department of Social and Health Services to have a medically determinable physical or mental impairment that, except for the applicant's ability to perform gainful activity, is comparable in severity to a disability that would qualify the applicant for SSI and Medicaid coverage; (5) be willing to submit to examinations that the Department considers necessary to establish the extent and nature of the applicant's disability; (6) need attendant care as determined by the Department using a client review questionnaire; (7) have earned income of less than 40% of the state median income (\$423/month for a single person) after subtracting work expenses, the cost of chore services, any medical expenses that are not covered by insurance or another source, and medical expenses incurred to allow the disabled person to work; a disabled recipient may choose to deduct either 20% of his/her gross income as work expenses or his/her actual work expenses; (8) have unearned income of less than 40% of the state's median income; (9) have resources (real or personal property) of \$10,000 or less for a single person and \$15,000 or less for a two-person family; an increment of \$1,000 per person is permitted for each additional family member; (10) agree to report promptly, in writing, any changes in income or resources that may affect eligibility; (11) agree to pay all attendant care services costs in excess of the state's

contribution; and (12) be at risk of being placed in a residential facility if attendant care services are not provided.

The state's contribution is based on the disabled person's earned income as follows:

<u>Percentage of State Median Income (after deductions listed in (7) above)</u>	<u>Percentage of Monthly Rate of Attendant Care Services Paid by the Department</u>
Between 0% and 10%	90%
Between 11% and 20%	80%
Between 21% and 30%	70%
Between 31% and 40%	60%

The disabled person hires his/her own attendant and may pay him/her up to \$3.75 an hour. The program permits a disabled person to hire a relative to provide attendant care services, but payment will be made to a spouse, mother, father, son, or daughter only if that person has to give up, or would otherwise have to take, paid employment of more than 30 hours a week to provide the service, or would otherwise be eligible for general assistance.

The Department pays its share of the disabled person's attendant care costs to the disabled person after the Department receives documentation that the disabled person received the services. The Department will pay no more than the lesser of \$510 a month or the cost of the services calculated from the following table:

<u>Hours of Service Per Day</u>	<u>Payment Per Day</u>
16-24	up to \$17
12-15	up to \$15
8-11	up to \$12
4-7	up to \$8

<u>Hours of Service Per Day</u>	<u>Payment Per Day</u>
2-3	up to \$5
1	up to \$3

The Department estimates that there are presently 20 persons in the program. No other data are available.

VIII. Rhode Island

Rhode Island's subsidy program uses state and federal Title VII B moneys to pay for attendant care for 29 persons who are unable to meet the cost of that care. The average weekly cost per person is \$113.75. Participants indicate that they have experienced improvement in health, personal care, employment outlook, and quality of life.

To administer its personal care services program, the Rhode Island Department of Social and Rehabilitation Services has contracted with the Paraplegia Association of Rhode Island (PARI), which operates the state's only Title VII B independent living center for severely physically disabled people (for a discussion of these centers, see Chapter 2). While the Department has final responsibility for the program, PARI evaluates applicants and acts as a conduit for the state and federal moneys that are used to pay for attendant care. The annual budget for the program is \$142,000. Of that, \$70,000 is a state appropriation, and \$72,000 is from the federal government as a line item in the independent living center's Title VII B grant. None of these moneys are used for administration.

A participant in the program must be determined to be eligible for it by an evaluation team consisting of a registered nurse, occupational therapist, and case manager from the independent living center, get an authorized service plan from those administering the program, be capable of directing his/her personal care services, and not have sufficient income or resources to

meet the cost of his/her home care. Employability is not a requirement for participation. If a person is accepted into the program but needs training in order to be an employer, the center will provide it. A participant must advertise for, select, and train his/her own attendant. S/he may hire a family member who does not live in the same household.

Under the program attendants are considered to be self-employed consultants. They are paid by the participants who receive the attendants' verified wages from PARI and who are responsible for handling withholding. The program pays up to \$3.50 an hour for a maximum of 35 hours per participant per week for personal care services; it also pays \$5.00 per night for a night attendant. PARI calculates into the cost of the care \$.19 per hour for preparing the invoices used to determine attendants' wages. Rhode Island currently has 29 persons who use its program to receive an average of 32½ hours per week of personal care services at an average weekly cost of \$113.75.

The program is permanent and has been in existence for two years. A spokesperson for it told the staff that during the first year, the program experienced a 60% to 70% turnover rate of attendants because the recipients were inexperienced as employers and because gasoline prices increased, making attendants less willing to travel to the recipients' homes. The turnover rate has since decreased as participants improve as employers. The spokesperson said that the program hopes to increase the hourly wage to \$4.00 or \$4.50 to decrease the turnover even more. A second problem at the beginning of the program was the attitude of some of the participants who "were used to being waited on" and wanted this to continue. The program now stresses that participants are expected to increase their independence through their receipt of public-funded personal care services, and the attitude problem has disappeared.

On the positive side the spokesperson indicated that the program "has done so much" for severely physically disabled people in Rhode Island. In March, 1981, PARI surveyed its personal care assistance program participants to gauge the program's impact. The results indicated that the participants experienced "substantial improvement" in health, personal care, employment outlook, and quality of life. Additionally, the survey compared the costs of hospitalization, visiting nurse association or homemaker visits, and private duty nurses for the respondents before and after they entered the program and found a 50% reduction in these costs as a result of the program.

IX. Connecticut

Connecticut pays up to \$4,000 per year for attendant care for employed severely physically disabled persons and up to \$2,000 for six months for employable persons. Recipients cannot earn more than \$18,000. Eleven persons are in the program. In spite of problems with the funding limits of the program, it is popular with the clients.

Under Connecticut's personal care assistance program, which began as a pilot program in 1979 and is now permanent, the Department of Human Resources pays up to \$4,000 per year for personal care services for each participant who is employed ("employed" has the same definition as in Vermont) and up to \$2,000 for no more than six months for each participant who is employable and actively seeking employment or who is unable to seek or accept employment because of a lack of personal care assistance. If the latter type of recipient finds employment during the six-month period, s/he may begin receiving the annual stipend; if s/he does not, s/he is dropped from the program.

In order to qualify for the program, an applicant must need at least one personal care service for at least two hours every day, be ineligible for any other state or federal personal care assistance, have an annual net income of

not more than \$18,000, and be able to provide a monetary or in-kind match equal to the amount s/he receives under the state subsidy program. Once a severely physically disabled person is accepted into the program, s/he must locate and train his/her attendant. The client, attendant, and Commissioner of the Department of Human Resources sign a contract that provides for the use of the moneys that the client will receive; the amount of moneys is determined on an individual basis. That amount, which cannot exceed the limits discussed above, is then sent to the participant in a lump sum, and the participant uses it to pay his/her attendant.

Connecticut's program is currently serving eleven severely physically disabled persons. It is funded completely with state moneys. The most current expenditure figures that the staff was able to obtain are \$16,000 for fiscal year 1980 and \$22,000 for the first half of fiscal year 1981.

A spokesperson for the program noted several difficulties with it. First, \$4,000 may not be enough to pay for all of some people's needed personal care services, and, rather than participate in a program that is inadequate to meet all of their needs, these people choose not to apply at all. Second, the requirement that participants provide a match for the state subsidy is a deterrent for some persons. Third, according to the spokesperson, the \$18,000 income limit does not allow for family incomes, and the program thus serves only single people or people who are "on their own." Finally, participants are experiencing some problems in finding attendants. However, the spokesperson also indicated that the program is receiving a great deal of support from clients and that the Department is hoping for an increase in state appropriations and is studying the possibility of using some Title XX moneys in the program.

X. Illinois

Illinois's Department of Rehabilitation Services operates a state-funded Home Services Program through which persons who are facing institutionalization may receive subsidized personal care services. Approximately 768 severely physically disabled persons are receiving those services at a monthly cost of slightly over \$263,715. The Department has calculated a monthly public savings of \$350 per client.

In 1978, Illinois began an In-Home Care Supportive Services Program in the Department of Public Aid. The program was divided and transferred in 1979 to the Department of Rehabilitation Services (DORS) for persons under age 60 and the Department on Aging for persons over that age. The move to DORS was made by the state to stress independent living for disabled persons; because of this emphasis, the staff focused on that department's Home Services Program.

The program, which is currently state-funded, provides chore housekeeping, homemaker, and home health services to persons who are medically and financially eligible. A person must be unable to pay for home care services and must need those services in order to stay out of an institution. As part of the application process, a service plan is written by the Department for each applicant. The plan delineates the person's needs and determines the cost of services to meet those needs. The state will pay for the services if their cost does not exceed the cost of putting the recipient into an institution. If the service's cost is greater than the cost of institutionalizing the person, s/he has the option of participating in the program by paying for the additional cost.

Attendant care is provided through the chore housekeeping component. A participant is responsible for hiring his/her attendant although the

Department will assist him/her in locating one. The client may hire a family member unless s/he is legally responsible for the client. The Department also pays the attendant after receiving from the client and verifying a voucher for the number of hours worked by the attendant; the Department withholds only social security from the check. In spite of the fact that the Department, and not the recipient, gives the check to the attendant, it still considers the recipient, and not itself, to be the attendant's employer.

Eighty per cent of the clients in the Home Services Program use chore housekeeping, and 48% of those are severely physically disabled persons. Illinois is subsidizing attendant care for approximately 768 severely physically disabled persons per month. Very few of these persons are employed. The average number of hours provided per month is 96 at a cost of \$343.38 per client. The total cost per month for severely physically disabled persons is slightly over \$263,715. The Department is investigating the possibility of using Medicaid moneys for the program.

By comparing the assessed institutional cost for a client with the projected cost of providing services for the client through the Home Services Program, the Department has calculated a monthly public savings of \$350 per client. This figure does not represent the savings for attendant care by itself; that figure is unavailable. According to a spokesperson for the program, the only difficulty with it has been administering the payment process. Until that process was operating smoothly, attendants experienced delays of up to six weeks in receiving their wages. The spokesperson thus recommended refining the payment process prior to the beginning of a program.

CHAPTER 8. EVALUATION

I. Introduction

This chapter first discusses the possible benefits of and problems with providing financial assistance for personal care services for severely physically disabled persons as well as the demand for that assistance in this state. It then briefly reviews the provision of assistance in Ohio. Finally, it presents the staff's findings concerning the need for additional assistance in this state.

II. General Discussion of Financial Assistance for Personal Care Services

Both providers and recipients of financial assistance for personal care services could benefit from it, but a few problems could arise in providing it. The demand for such financial assistance in Ohio is great.

The use of public moneys to assist in the provision of personal care services for severely physically disabled people could have tangible and intangible benefits for both the providers and the recipients of the moneys. In Ohio the statewide average of personal care costs in institutions, excluding medical care costs, is \$57.50 per person per day. States that are subsidizing in-home attendant care are paying considerably less than that amount in their programs (for example, see the discussions of Massachusetts and Vermont in Chapter 7). Thus, for the governmental entity or entities that provide financial assistance for personal care services, a savings in public moneys might occur if a recipient were able to leave an institution as a result of the assistance. Additionally, new tax revenues could be generated if a recipient or a member of a recipient's family who is currently

staying home to provide attendant care were able to enter the job market because of the assistance. Finally, society in general could be improved if severely physically disabled persons who are currently residing in the often stultifying atmosphere of many institutions were free to use their talents and become contributing citizens.

Recipients of financial assistance could also benefit from the opportunity to use their talents that the assistance could provide. In addition, they could have the chance to lead a more independent life by leaving institutions or their families' homes and having control over their personal care services if the financial assistance were provided in such a way that the recipients were allowed to select, train, and dismiss their attendants. Third, a severely physically disabled person could experience an enhancement of his/her dignity if the financial assistance enabled the person to be in charge of his/her personal care and/or to make decisions about the future. These activities, which are conducted and frequently taken for granted by many able-bodied adults, are important for a disabled person's sense of independence and self-esteem. Fourth, families that have a severely physically disabled member and that try to provide that person's care by themselves frequently experience a great deal of stress, which in turn can lead to a splintering of the families or the institutionalization of the member. Financial assistance for personal care services could help to alleviate that stress and its consequences. Finally, a severely physically disabled person who would be able to acquire gainful employment because of aid with his/her attendant care could gain an improved standard of living.

Several problems could exist with a program to provide public moneys for personal care services. The program might not be cost effective because, even though a severely physically disabled person might be able to leave an

institution, s/he might still need financial assistance with medical expenses and housing, for example, in addition to attendant care. Additionally, if the program were not organized well before it was implemented, it could create numerous administrative difficulties.

Finally, in order to meet the goals of independent living and employment, attendants, accessible housing, and jobs would need to be available. The staff learned that in Ohio attendants are most likely to be available in metropolitan areas that have colleges or universities and thus large student populations. Difficulty in locating attendants occurs in rural areas, small towns, and even some cities that do not have colleges or universities. The Ohio Rehabilitation Services Commission study, Disabled Ohioans: Their Housing and Employment Needs; Preliminary Report, published in October, 1981, indicated that problems exist with both accessible housing and jobs. Accessible housing is especially limited in urban areas, which have larger numbers of disabled persons than do rural parts of the state. Jobs exist for which disabled persons are qualified, but the depressed state of the economy and discrimination by employers hamper the employment of those persons. Also, a lack of adequate transportation frequently exacerbates both housing and employment difficulties. Thus, problems with locating attendants, accessible housing, and jobs could lessen the potentially positive impact of a program of subsidized attendant care in Ohio by frustrating recipients who might have hoped for an immediate change in their lives.

Nevertheless, the demand in the state for additional financial assistance for personal care services is great. While conducting the research for this study, the staff was in contact with severely physically disabled persons, consumer groups representing them, persons at state universities and at hospitals with rehabilitation centers who work with them, and state agencies

that provide services for them. When asked by the staff if additional funding sources were needed for attendant care, the overwhelming response from all these groups was a definite yes (see Appendix D for a statement of need by the Rehabilitation Services Commission). Many persons stated that a lack of help with personal care services is one of the greatest problems facing severely physically disabled Ohioans.

III. Review of Assistance Available in Ohio

Financial assistance for personal care services is limited in Ohio, especially for persons who want to work and/or live independently.

The availability in Ohio of financial assistance for personal care services that fosters employment and independent living as well as allows a recipient to control his/her own care is limited. The Rehabilitation Services Commission subsidizes attendant care only for persons who are participating in a Bureau of Vocational Rehabilitation/Bureau of Services for the Visually Impaired rehabilitation program. When they complete the program, their subsidies end.

A severely physically disabled person can receive Title XX homemaker/home health aide services only if s/he meets income eligibility standards and only through a home health agency under contract with the person's county welfare department. However, home health agencies are in great demand in Ohio. This means that they usually cannot provide services on a daily basis. Because they offer professional services, their rates are high. Finally, they are not available in all parts of the state. As a result of the federal Omnibus Budget Reconciliation Act of 1981, Ohio could use Title XX moneys to fund a personal care assistance program that does not have the above restrictions; however, that would entail reducing Title XX funds for other services currently in existence.

Federal guidelines permit the cost of attendant care to be excluded from a person's income when determining Supplemental Security Income eligibility; they also establish personal care as an optional Medicaid service. Neither of these provisions is part of Ohio's Medicaid program. Thus, income-eligible severely physically disabled Ohioans receive Medicaid assistance for personal care services only if those services are provided as a home health service by a home health agency. As discussed above, problems exist with the use of home health agencies to provide attendant care. Finally, Medicaid home health services must be part of a physician's written plan of care for a person, and the service provider is paid directly by the Department of Public Welfare. Both of these elements reduce the recipient's control over his/her care.

In order for a severely physically disabled person who is under age 65 to receive Medicare assistance with personal care services, s/he must have been receiving social security disability insurance for at least two years, need skilled care in addition to the attendant care, and be homebound. These requirements mean that a severely physically disabled person who needs only attendant care in order to work probably would not receive assistance under Medicare.

The only other available financial assistance for Ohioans is through the Veterans Administration, for veterans; through the Department of Housing and Urban Development (HUD), if a disabled person lives in HUD-assisted housing that provides a round-the-clock attendant; and through the Bureau of Workers' Compensation, if a person was injured on the job.

All of the above programs contain either eligibility or disbursement limitations that prevent them from being ideal sources of financial assistance for Ohio's severely physically disabled persons who need that kind of

help with personal care services. Because of these limitations, they provide assistance for only a limited number of people. However, the programs do provide at least a small amount of assistance for some Ohioans.

IV. Conclusions

The sources of financial assistance in Ohio for personal care services are not adequate to meet the needs of the state's severely physically disabled population. This is evident after reviewing those sources and talking with both severely physically disabled consumers and professionals in the area. Additional assistance is needed if these citizens are to lead more independent lives and/or enter the job market.

The staff cannot state unequivocally that an eventual net savings in state and/or federal moneys would occur if Ohio were to subsidize attendant care for some or all of its severely physically disabled citizens. The only way to determine if such a savings would occur in Ohio would be to implement a program in this state and monitor it closely during its first years of operation to determine its fiscal effect. However, based on the experience of several other states (again, see Chapter 7), the possibility of a savings in public moneys exists.

Additionally, a problem might exist if the state began to subsidize attendant care only to learn that there were insufficient numbers of attendants, accessible housing, and jobs. However, the opening of two centers for independent living in the state as well as the effort to open additional centers (see Chapter 2) indicates an awareness of this problem and an attempt to deal with it.

Finally, a state-subsidized program of attendant care could have unquantifiable benefits for both the recipients and their families. The recipients could experience an improved quality of life through having

control over their lives and using their skills and talents to their maximum potential. Their families could undergo a lessening of stress and tension, and some members could return to their careers and interests. The state in turn might benefit from the contributions of all of these people. In fact, most other states that have specific personal care assistance programs (for example, see the discussion of Rhode Island in Chapter 7) view the programs as an important social service; any savings in public moneys through them are merely an added benefit.

CHAPTER 9. PROGRAM ALTERNATIVES

I. Introduction

Amended House Joint Resolution 91 of the 113th General Assembly, which requested this study, stipulated that the study should include an examination of the relative costs and benefits of establishing state subsidies for personal care services (see Chapter 8), an evaluation of alternative designs for a state subsidy program, and a consideration of what agencies might administer a program. However, on November 19, 1981, the 114th General Assembly enacted Am. Sub. H.B. 552, which contained, among other provisions, a requirement that the Rehabilitation Services Commission establish and administer a program to provide personal care assistance to enable eligible severely physically disabled persons to live independently or work. Thus, the question of what state agency or agencies should administer a state subsidy program is now moot.

This chapter thus discusses possible funding sources for personal care services and presents alternatives for organizing and administering an attendant care program. The latter presentation includes the staff's suggestions concerning which alternatives might be most effective. The chapter also presents the staff's estimate of how much a state-subsidized program could cost.

II. Possible Funding Sources

Amended Substitute House Bill 552 required the Rehabilitation Services Commission (RSC) to use "funds appropriated for that purpose" to establish a personal care services program. However, no funds were specifically

appropriated for the program, and RSC is investigating what moneys are available for it to use in administering the program.

A program that uses public moneys to pay for personal care services could be funded in several ways. Following are possibilities that the state might consider to provide moneys for such a program. The staff has included explanatory comments as needed.

--The General Assembly could make a specific appropriation to RSC for the program.

--RSC could use moneys in its budget that have been earmarked for other programs. This might mean a decrease in services offered by those programs.

--RSC could apply to the federal Rehabilitation Services Administration (RSA) for a special demonstration programs grant (see Chapter 2). Such a grant could be used to fund a pilot project or perhaps a particular aspect of the personal care services program. Because of the length of time needed to apply for and receive a grant and because federal funds in general are becoming less available, the state probably should not rely on such a grant as a source of initial funding.

--RSC could increase its effort to obtain grants for independent living centers (ILC's) from RSA (again, see Chapter 2). Existing and future ILC's might be able to include in their budget proposals line items for the direct payment of attendant care for severely physically disabled persons. In addition, ILC's help locate attendants, accessible housing, and jobs; these activities are not directly related to the funding of a personal care services program, but they do assist the operation of such a program. However, RSC's grant proposal for ILC's in Dayton and Columbus was rejected; similar rejections in the future could limit the feasibility of using ILC grant moneys to subsidize personal care services.

--The Department of Public Welfare could use Title XX moneys to pay for personal care services. With the elimination of restrictions on the use of Title XX moneys brought about by the Omnibus Budget Reconciliation Act of 1981, Title XX could be an ideal source of funding if the state wanted to use all federal moneys to pay for attendant care. However, all of Ohio's Title XX allocation is being used by existing programs; moneys for a personal care services program would have to be taken from them. This withdrawal of funds would be in addition to the general cutback in federal funds occurring at the time of this report. In addition, if Title XX moneys were used for this purpose, the program would probably be administered by the Department of Public Welfare.

--The Department of Public Welfare could amend Ohio's Medicaid program to provide attendant care for unemployed severely physically disabled persons by adding personal care services as a Medicaid service and by applying to the federal government for a waiver to allow the state Medicaid plan to include home or community-based services (see Chapter 4). The use of Medicaid moneys in these ways would ensure at least partial federal participation in subsidizing attendant care. However, the federal government is trying to reduce Medicaid expenditures, and the Department of Public Welfare probably would need to evaluate these uses of Medicaid moneys in terms of cost savings in order to justify the uses. Additionally, the Department of Public Welfare, and not RSC, would have to administer this type of program.

III. Program Alternatives

Amended Substitute House Bill 552 requires RSC to establish and administer a personal care services program for severely physically disabled persons. The General Assembly's intent seems to be the creation of a program geared specifically to providing assistance with attendant care. The staff

thus prepared alternatives for such a program. Guidelines are already in place for the use of Medicaid moneys, for example, should the state decide to change its Medicaid program to include personal care services.

Persons To Be Served

Prior to the enactment of Am. Sub. H.B. 552, this section would have discussed alternatives concerning what persons might be included in a subsidized program to provide personal care services. Such a discussion would have considered, for example, whether a program should provide services for employed severely physically disabled persons, severely physically disabled persons who live in or might have to enter institutions, or both. However, the applicable statute enacted by the above bill stipulates that personal care assistance funded under the program that is to be operated by RSC must enable eligible severely physically disabled persons to live independently or work. Thus, this topic need not be considered in detail in this report.

However, the staff suggests that, within the above guidelines, a personal care services program be established in phases. The first phase, which could last two years, could provide financial assistance for severely physically disabled persons who are employed or who could be employed if they received that assistance. These persons might best be able to direct their own care, and the administering agency would thus be able to implement the program and correct any difficulties with it while working with a group of people who would not need training in how to be an employer, for example.

Following this first phase, the program could then include persons who need financial assistance with personal care services in order to live independently but who cannot work. These persons, many of whom presumably are in institutions or who are at risk of institutionalization, might need close supervision initially in working with their attendants. A program that has

tough to control

goal: improve persons independence
think out - is there a conflict
or live live in improving a non-
disabled family members independence?
-82-
had time to have its difficulties worked out might be able to serve these people better.

*this is it - ?
not a phase*
As a third phase, the staff suggests that the administering agency consider expanding financial assistance to persons who need attendant care but who are unable to work or live independently. These persons would be primarily children or elderly persons who are living with their families and receiving personal care services from one or more family members. Under this third phase, financial assistance could be provided to families who want to keep their disabled member at home but are unable to do so because of financial difficulties and the emotional stress of providing attendant care by themselves. Financial assistance could also enable some family members to return to their careers who are currently staying home to provide personal care services. The staff suggests this phase could be implemented after the administering agency determines the costs and procedures of administering the first two phases. *Questionable*
this is it maybe?

Process for Evaluating Applicants

--An evaluation team organized expressly for the program's purposes could evaluate each applicant to determine that person's eligibility for the program.

--An applicant could present to the administering agency proof of an earlier evaluation by the Bureau of Vocational Rehabilitation/Bureau of Services for the Visually Impaired or, in the absence of such an evaluation, a statement of need from a physician.

The staff suggests the use of an evaluation team and further suggests that the team be composed of a registered nurse, an occupational therapist, and a severely physically disabled person who uses attendant care. Such a team could use consistent standards when evaluating applicants and also could

be used by the administering agency to establish a service plan for each applicant (e.g. number of hours of personal care services needed by the applicant).

Income Eligibility

--The administrator of the program could examine each successful applicant's income or, as appropriate, his/her family's income and determine if, after subtracting living expenses, medical expenses, and expenses unique to severely physically disabled persons, the applicant or his/her family is able to pay for any services the person needs beyond those that the program will subsidize (see Services, below) or for any services that could be subsidized by the program. The applicant or his/her family could then be required to pay for those services for which s/he or it is able.

--The administering agency could establish an income limit for applicants, either as a dollar figure or as a percentage of the state median income.

--The administering agency could use the formula devised by Massachusetts (see Chapter 7).

--The program could have no income eligibility criterion.

The staff suggests the use of the first alternative, which enables subsidies to be granted on a case-by-case basis. While this method is more time consuming than the other alternatives, the staff believes that it is also more fair because it allows a severely physically disabled person to receive the assistance that s/he needs, within the guidelines of the program (again, see Services, below), based on his/her or his/her family's unique financial situation. At the same time, the recipient is responsible for paying for as much attendant care as s/he or his/her family is able.

Use of Other Available Public Moneys

--The program could be used to subsidize attendant care only for those persons who are ineligible for any other state or federal moneys that could be used for this purpose.

--The program could disregard an applicant's eligibility for any other applicable state or federal moneys.

The staff suggests that the program funds be used only for applicants who are ineligible for other public moneys that could be used for this purpose.

Services

Amount of Care To Be Subsidized

--The administering agency could establish minimum and maximum numbers of hours of personal care services that it will subsidize per day, per week, or per month, excluding care provided by a night attendant.

--The administering agency could subsidize care provided by a night attendant on a per-night basis.

--The administering agency could subsidize any amount of attendant care needed by an applicant.

The staff suggests that the administering agency subsidize fourteen to 35 hours of personal care services per person per week for services rendered during the day. This limitation has been used and found to be effective by several other states (see, for example, the discussion of Rhode Island in Chapter 7). The staff also suggests that the administering agency monitor this limitation on hours during the program's initial months of operation to determine if different specifications might be more beneficial to the program's participants. The monitoring could include a lowering of the minimum number of hours to learn if that amount of assistance is useful to anyone.

Finally, the staff suggests that the administering agency also subsidize care by a night attendant on a per-night basis.

Compensation for Attendants

--The program could pay day attendants on an hourly basis.

--The program could pay night attendants on a per-night basis.

--The program could pay all attendants a daily wage.

--The program could provide each recipient with a yearly stipend and allow that person to pay his/her attendant or attendants however s/he chose to do so.

The staff suggests that day attendants be paid \$4.00 to \$4.50 per hour. This amount would enable an attendant to net approximately the minimum wage after allowing for the necessary withholdings. The staff also suggests that night attendants be paid \$6.00 per night. Both of these figures are based on the experiences of other states (again, see Chapter 7). By establishing set fees for services provided, the administering agency should be able to monitor quite closely the amount and costs of services paid for by the program.

Payment of Attendants

--The administering agency could send an attendant's paycheck to the severely physically disabled person who employs him/her after receiving verification of the number of hours worked by the attendant; the severely physically disabled person could in turn pay his/her attendant.

--The administering agency could pay an attendant directly after receiving verification of the number of hours that s/he worked.

The staff suggests that the administering agency allow each severely physically disabled person to pay his/her attendant in order to foster the

ideas that the severely physically disabled person is the attendant's employer and that s/he is in charge of his/her own care.

Withholding from Attendants' Paychecks

--The administering agency could do the paperwork necessary to withhold taxes, social security, and workers' compensation from attendants' paychecks and could issue the paychecks with those items already withheld.

--The recipients of the financial assistance could be responsible for their attendants' withholding.

The staff suggests that the administering agency be responsible for attendants' withholding both to assist the severely physically disabled participants and to ensure that the necessary items are withheld.

Selection of Attendants

--The program could allow a severely physically disabled person to hire any person of his/her choosing as an attendant.

--The program could encourage a severely physically disabled person to hire as an attendant a person who is unemployed and receiving public assistance.

--The program could allow a severely physically disabled participant to hire any person as an attendant except a member of his/her family.

--The program could require a severely physically disabled person to hire as an attendant a person who is unemployed and receiving public assistance.

--The administering agency could select a severely physically disabled person's attendant for him/her.

Because of the personal nature of attendant care, the staff suggests that the program allow a severely physically disabled participant to select his/her attendant. This could include a member of the person's family. By

enabling a family member to serve as an attendant, the program would permit the participant to have as an attendant someone who is already familiar with his/her care. In addition, the family member would receive remuneration, thus aiding the family's financial status, perhaps alleviating stress by compensating the family member, and providing for the family member's future through social security withholding. The staff recognizes that a personal care services program could be a source of jobs for persons who are currently receiving public assistance. The staff thus suggests that the program encourage participants to hire such persons as attendants and that the administering agency establish a roster of such persons and provide training for them.

IV. Cost Estimate

In the absence of an operational state-subsidized program to provide personal care services for severely physically disabled persons or of proposed specifications for such a program, estimates of the cost of a state-subsidized program are at best educated guesses. The staff applied data from other states' experiences to Ohio and used the suggestions discussed above concerning the amount of care to be subsidized and compensation for attendants to arrive at dollar figures that give only an idea of the possible cost of a program in Ohio.

From the states described in Chapter 7, the staff selected those that use state moneys to fund a personal care services program. It then calculated the percentage of each state's population that the state's program serves and applied each of those percentages to Ohio's population. For example, Illinois's program serves .00007% of that state's population, or 768 persons; a program in Ohio that would serve the same percentage of this state's population would assist 756 persons. By averaging the results of the application

of these percentages to Ohio, the staff determined that, under this formula, the number of Ohioans served served by a state-subsidized program would be 336. This number could be quite low because participation in some other states' programs is minimal and response to a program in Ohio might be higher than those states' experiences would indicate. The staff also used the above formula to determine a low number of Ohio participants, 43, and high number, 756.

As discussed above, the staff is suggesting that an attendant care program subsidize fourteen to 35 hours of care per week at \$4.00 to \$4.50 per hour. The staff used these figures to determine a yearly low, average, and high subsidy for a program participant. The low subsidy was calculated by multiplying fourteen hours by \$4.00 per hour by 52 weeks, the average by multiplying 25 by \$4.25 by 52, and the high by multiplying 35 by \$4.50 by 52. The results are \$2,912, \$5,525, and \$8,190, respectively.

The following table shows the amount of money needed to fund personal care services at the above levels for a low, average, and high number of Ohioans. The staff stresses that these figures are merely estimates and should not be interpreted as actual program costs.

Annual Cost Per Person	Number of Persons To Be Served		
	43	336	756
\$2,912	\$125,216	\$ 978,432	\$2,201,472
\$5,525	\$237,575	\$1,856,400	\$4,176,900
\$8,190	\$352,170	\$2,751,840	\$6,191,640

APPENDIX A.

MAXIMUM INCOME LEVEL FOR SOCIAL SERVICE ELIGIBILITY IN OHIO UNDER TITLE XX

FAMILY SIZE	FREE SERVICES GROSS INCOME		FAMILY SIZE	FEE SERVICES GROSS INCOME	
	MONTHLY	ANNUALLY		MONTHLY	ANNUALLY
1	457	5,486	1	665	7,982
2	598	7,174	2	870	10,438
3	739	8,862	3	1,075	12,894
4	879	10,550	4	1,279	15,350
5	1,020	12,238	5	1,484	17,806
6	1,161	13,926	6	1,689	20,262
7	1,187	14,243	7	1,727	20,723
8	1,213	14,559	8	1,765	21,183
9	1,240	14,876	9	1,805	21,664
10	1,266	15,192	10	1,842	22,104
11	1,292	15,509	11	1,880	22,565
12	1,319	15,825	12	1,919	23,025
13	1,345	16,142	13	1,957	23,486
14	1,372	16,458	14	1,996	23,946
15	1,398	16,775	15	2,034	24,407
16	1,424	17,091	16	2,072	24,816

(from Ohio Title XX Comprehensive Annual
Services Plan, July 1, 1981-June 30, 1982)

APPENDIX B.

SCHEDULE OF PARTIAL PAYMENTS FOR SOCIAL SERVICES IN OHIO UNDER TITLE XX (For Families of One to Six Members)

Family Monthly Gross Income		Monthly Dollar Amount Available For Services	Monthly Dollar Fee For One Service	Additional Monthly Dollar Fee For Two Services	Additional Monthly Dollar Fee For Three or More Services
From	Thru				
Family of One					
458	484	15	5	5	5
485	510	18	6	6	6
511	536	21	7	7	7
537	562	24	8	8	8
563	588	27	9	9	9
589	614	30	10	10	10
615	640	33	11	11	11
641	665	36	12	12	12
		27			

Family Monthly Gross Income		Monthly Dollar Amount Available For Services	Monthly Dollar Fee For One Service	Additional Monthly Dollar Fee For Two Services	Additional Monthly Dollar Fee For Three or More Services
From	Thru				
Family of Two					
599	632	18	6	6	6
633	666	24	8	8	8
667	700	30	10	10	10
701	734	33	11	11	11
735	768	36	12	12	12
769	802	39	13	13	13
803	836	45	15	15	15
837	870	48	16	16	16

Family of Three					
740	781	27	9	9	9
782	823	30	10	10	10
824	865	36	12	12	12
866	907	42	14	14	14
908	949	48	16	16	16
950	991	51	17	17	17
992	1033	54	18	18	18
1034	1075	57	19	19	19

Family of Four					
880	930	33	11	11	11
931	980	36	12	12	12
981	1030	39	13	13	13
1031	1080	45	15	15	15
1081	1130	51	17	17	17
1131	1180	57	19	19	19
1181	1230	63	21	21	21
1231	1279	69	23	23	23

Family Monthly Gross Income		Monthly Dollar Amount Available For Services	Monthly Dollar Fee For One Service	Additional Monthly Dollar Fee For Two Services	Additional Monthly Dollar Fee For Three or More Services	Family Monthly Gross Income		Monthly Dollar Amount Available For Services	Monthly Dollar Fee For One Service	Additional Monthly Dollar Fee For Two Services	Additional Monthly Dollar Fee For Three or More Services
From	Thru					From	Thru				
Family of Five						Family of Six					
1021	1079	36	12	12	12	1162	1228	39	13	13	13
1080	1137	39	13	13	13	1229	1294	42	14	14	14
1138	1195	42	14	14	14	1295	1360	45	15	15	15
1196	1253	48	16	16	16	1361	1426	51	17	17	17
1254	1311	54	18	18	18	1427	1492	57	19	19	19
1312	1369	60	20	20	20	1493	1558	63	21	21	21
1370	1427	66	22	22	22	1559	1624	69	23	23	23
1428	1484	72	24	24	24	1625	1689	75	25	25	25

(from Ohio Title XX Comprehensive Annual Services Plan, July 1, 1981-June 30, 1982)

APPENDIX C. MATRIX OF AVAILABILITY OF TITLE XX SERVICES BY COUNTY IN OHIO

TITLE XX SERVICES	ADAMS	ALLEN	ASHLAND	ASHTABULA	ATHENS	AUGLAIZE	BELMONT	BROWN	BUTLER	CARROLL	CHAMPAIGN	CLARK	CLERMONT	CLINTON	COLUMBIANA	COSHOCTON	CRAWFORD	CUYAHOGA	DARKE	DEFIANCE	DELAWARE	ERIE	FAIRFIELD	FAYETTE	FRANKLIN	FULTON	GALLIA	GEAUGA	GREENE	GUERNSEY	HAMILTON	HANCOCK	HARDIN	HARRISON	HENRY	HIGHLAND	HOCKING	HOLMES	HURON	JACKSON	JEFFERSON	KNOX	LAKE	LAWRENCE				
ADOPTION	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
CAMPERSHIP	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
CHORE	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
COMMUNITY BASED CARE FOR ADULTS	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
COUNSELING	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
DAY CARE FOR ADULTS	X	X		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
DAY CARE FOR CHILDREN - Employment & Training	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
DAY CARE FOR CHILDREN - Protective			X	X	X	X	X		X	X	X	X	X	X	X	X	X	X		X	X	X			X	X	X		X		X	X	X	X				X	X	X	X	X	X	X	X	X		
DAY CARE FOR CHILDREN - Special Needs	X		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X			X	X	X		X	X	X	X	X		X	X	X	X				X	X	X	X	X	X	X	X	X		
DAY TREATMENT FOR CHILDREN	X		X		X	X	X		X	X	X	X	X	X	X	X	X	X	X		X		X		X		X	X		X	X	X	X	X				X	X	X	X	X	X	X	X	X		
DEVELOPMENTAL SERVICES FOR CHILDREN AND YOUTH	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
EMPLOYMENT AND TRAINING	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
FAMILY PLANNING	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
FOSTER FAMILY SPECIAL SERVICES FOR CHILDREN						X	X			X	X	X	X			X		X		X		X			X		X	X				X		X	X	X			X	X		X	X	X	X	X		
GUARDIANSHIP	X		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
HEALTH-RELATED SERVICES	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
HOME DELIVERED & CONGREGATE MEALS	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
HOME MAINTENANCE - HOME HEALTH AIDE	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
HOME MANAGEMENT	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
HOUSING	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
INFORMATION & REFERRAL	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
LEGAL	X				X		X	X		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
MENTAL RETARDATION ASSESSMENT	X		X		X				X	X	X	X	X		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X												

ADULT	X
CAMPERSHIP	X
CHURCH	X
COUNSELING	X
COMMUNITY BASED CARE FOR ADULTS	X
DAY CARE FOR ADULTS	X
DAY CARE FOR CHILDREN -	X
Employment & Training	X
DAY CARE FOR CHILDREN -	X
Protective	X
DAY CARE FOR CHILDREN -	X
Special Needs	X
DAY TREATMENT FOR CHILDREN	X
DEVELOPMENTAL SERVICES FOR	X
CHILDREN AND YOUTH	X
EMPLOYMENT AND TRAINING	X
FAMILY PLANNING	X
FOSTER FAMILY SPECIAL SERVICES	X
FOR CHILDREN	X
GUARDIANSHIP	X
HIGH-RELATED SERVICES	X
HOME DELIVERED & CONGREGATE MEALS	X
HOMEPART-TIME HEALTH AIDE	X
HOME NURSERY	X
HOURS	X
INFORMATION & REFERRAL	X
LEGAL	X
MENTAL RETARDATION ASSESSMENT	X
OTHER EDUCATIONAL SERVICES	X
PLACEMENT SERVICES FOR CHILDREN	X
PROTECTIVE SERVICES FOR ADULTS	X
PROTECTIVE SERVICES FOR CHILDREN	X
PSYCHIATRIC SERVICES	X
PREPAREDATIVE PAYEE	X
RESIDENTIAL TREATMENT FOR ADULTS	X
RESIDENTIAL TREATMENT FOR	X
CHILDREN	X
SERVICES FOR SUBSTANCE ABUSERS	X
ALCOHOLICS & DRUG ADDICTS	X
SOCIALIZATION/DEVELOPMENTAL	X
SERVICES FOR ADULTS	X
SPECIAL SERVICES FOR THE BLIND	X
SPECIAL SERVICES FOR THE	X
COGNITIVELY IMPAIRED	X

-v-

(from Ohio Title XX Comprehensive Annual Services Plan, July 1, 1981-June 30, 1982)

APPENDIX D.

REHABILITATION SERVICES COMMISSION STATEMENT OF NEED FOR ATTENDANT CARE PROGRAM

In the absence of specific data, the following general statement can be made:

A major criterion for eligibility for services requires that a client be employable following a program of vocational rehabilitation. If it is determined at the onset that a client's employment and income potential is not at a level to make it economically feasible for the client to pay for attendant care, the client is considered too severely disabled and is not found eligible for services. Similarly, some clients face the loss of other benefits should they become employed and may not wish to become employed if there is more to lose than to gain. This situation is also taken into consideration at the time of eligibility determination.

It is not surprising that most of our clients currently receiving attendant care services are individuals with higher IQ's although otherwise quite severely physically disabled, e.g., quadraplegia, and cerebral palsy. This group has the potential to prepare themselves for a profession or vocation that would offset the disincentives to employment. These clients only receive attendant care services during their vocational rehabilitation programming. For even this group, ongoing attendant care following vocational rehabilitation would greatly provide financial relief to individuals and families for whom the disability imposes a high cost in other ways such as transportation, equipment, ongoing therapy and other medical costs.

If ongoing attendant care were available, a considerable number of other individuals would be good candidates for employment possibilities at lesser earning levels, e.g. clerical and office-related, etc. Although the income might be slightly more than the minimum wage, other incentives would prevail, especially in cases where other benefits would not be affected.

PM & R centers report only a small number of patients (5%) end up in long-term care facilities following discharge. This means that a number of family members assume attendant care responsibilities, either directly or by hiring personnel. Aside from a cost burden on the family, it places the individual in a position of dependency. Ongoing attendant care for many is seen as one way that individuals could begin to think about independent living, employed or not. Many family members who are getting up there in years are not able financially, physically and psychologically to cope with the demands of caring for family members who are severely disabled.

It is the general feeling among severely disabled people in Ohio that homemaker/health aid services provided under Title XX and Medicaid programs do not meet the basic needs of severely disabled people. The services are limited, foster dependency and eventually relegate people to institutions and serve as disincentives to independent living and employment.

RSC believes a strong case can be made for subsidized attendant care.



THE INSTITUTE FOR EDUCATIONAL LEADERSHIP, INC.

July 1982

MEMORANDUM

TO: Participants/Independent Living Leadership Strategies
Project

FR: Margot Gold

RE: Resource Guide/Issues in Program Management
and Program Evaluation

The planning committee for the strategic planning session thought it would be helpful to participants if we identified major sources of information currently available in the areas of program management and program evaluation. While time and resources did not permit an exhaustive search, we hope the information contained in this paper is useful to you.

CONTENTS

I. Management

- Issue/Discussion
- Management Resources
- "Summary of Trends and Their Implication for Independent Living Management" (Lundgren and Ziskind)
- "Registry of Independent Living Programs"
- "Accountability and Management" (Shreve, Rehabilitation Gazette)
- Suggested Resources

II. Evaluation

- Issues/Discussion
- Examples of Evaluation Questions/Forms
 - A. Washington State Evaluation Project
 - B. California State Department of Rehabilitation
 - C. New York and Pennsylvania Statewide Questionnaires
 - D. RSA Draft Guidelines
 - E. Quarterly Cost Data Form (Tim Muzzio)

I. MANAGEMENT

ISSUE: PROPER MANAGEMENT OF ILPS, LIKE OTHER NON-PROFIT ORGANIZATIONS, IS CRITICAL TO LONG TERM SURVIVAL. WITH SHRINKING FEDERAL SUPPORT CAUSING THE SHIFT TO SMALLER AND LESS PREDICTABLE PRIVATE SOURCES OF FUNDING, MANAGEMENT ISSUES OF ILPS BECOMES MORE IMPORTANT.

Today, with shifting federal priorities, the effective management of ILPS is of critical importance. Management has become more difficult since long range planning is hampered by the uncertainty of federal and private funding.

The search for alternate funding sources takes time and money. Since private grants rarely approach the funding level of federal grants, an increase in the number of small grants is necessary to make up the difference. Managers are often faced with the dilemma of having to decide whether to use monies that otherwise would go into services for fund seeking or development activities.

Another dilemma that makes program planning and administration difficult is that the most needed service may turn out to be the most difficult to find. Discretionary money from private sources is extremely difficult to find. As a result, a manager may lose partial decisionmaking control over program direction, emphases or services.

Innovative ideas (such as adjunct businesses) are needed to generate money "without strings" so that resources can be spent according to the needs prioritized by program decisionmakers, rather than preferences of external groups. However, there is a Catch 22 at play here. Innovative ideas require start-up capital, and during initial implementation, adjustments and refinements are often necessary, all of which add up to the need for additional time and resources. Often new strategies fail, or a considerable amount of time passes before benefits are realized. Organizations need slack in their budgets to encourage and implement new ideas. Now, when programs need new methods most, their economic positions make exploration and development impossible. This Catch 22 not only applies to funding strategies but also to other changes a manager may want to implement.

One way to help break the Catch 22 cycle is to limit the guess work involved, by sharing information and experience with other ILPs, as well as with other non-profit, grass roots organizations. Of course, it would be most instructive for a manager to find parallel groups in size, age, staffing, services, and environment. As this is not always possible, representatives should keep in mind the differences between groups, so strategies can be adapted, and accepted or rejected. This type of exchange among ILP representatives is one objective of our sessions, and is represented in the agenda under the headings of "organizational histories" and "operational/organizational clinics."

MANAGEMENT RESOURCES

The Independent Living Research Utilization Project (ILRU) in conjunction with Cornell University's Human Services Administration Program, has conducted a number of management simulation training sessions for directors of independent living programs nationwide. The results of these sessions are synthesized in the attached paper, "Summary of Trends and Their Implications for Independent Living Management". Also included in this section are a list of recommended resources for managers developed by the Cornell team, a review of management related resources written specifically on ILPs, and a copy of an article, "Accountability and Management - An Open Letter to Directors" that was included in the 1981 issue of the "Rehabilitation Gazette."

For more information on the training sessions, you can contact either:

Lex Frieden
Project Director
Independent Living Management Project
Independent Living Research Utilization Project
The Institute for Rehabilitation and Research
P.O. Box 20095
Houston, Texas 77025

Ronald House
Program Director
Human Services Administration Program-
N.Y. State School of Industrial and Labor
Relations
P.O. Box 1000
Ithaca, NY 14853
(607) 256-7727

Lex Frieden will also be able to provide information on the technical assistance capabilities of the ILRU. It is my understanding that Board Training, Staff Development, and an orientation program designed for communities on independent living, are three of a number of training sessions provided by ILRU staff.

In addition to the general management material recommended by Cornell, one other report specifically directed to ILPs should also be considered.

Implementation of Independent Living Programs in Rehabilitation is a report whose primary aim is to provide a resource for managers in the planning, development, and operation of ILPs, which was developed as a result of a meeting of the Planning Committee of the Institute for Rehabilitation Issues in 1979.

I would recommend ordering this report for Chapter IV alone, which is on "Supporting an Independent Living Program." This is not to take away from sections on Staffing, Program Evaluation, or Staff Training. Chapter IV, however, is the most comprehensive and clear presentation I've seen on funding alternatives and resources. The chapter begins with descriptions of federal programs. The uniform format used to describe each program is structured by a series of questions which include: "What are the program goals? What services can be provided? How to access program funds or services? How to learn more?" Following this section there are three discussion sections on Foundations, Corporations, and Other sources of support. The chapter ends with a bibliography.

This report is available from the Arkansas Rehabilitation Research and Training Center, University of Arkansas, Arkansas Rehabilitation Services, Hot Springs, Arkansas, 71901. Douglas Rice was the University sponsor of this paper.

ILRU SOURCEBOOK

Justin Dart describes the ILRU Sourcebook in his literature review of independent living programs in a forthcoming report on ILP management written by Peg Nosek and Justin and Yoshiko Dart. As I have not had the opportunity to read the book, the comments that follow are directly from Mr. Dart's review.

The ILRU Sourcebook by Frieden et al is a compendium of valuable information geared toward individuals wishing to develop an ILP in their community. It contains a glossary of terms related to independent living which have set the standard for the field, a discussion of possible ILP models, a registry and brief profile on the ILPs operating in 1979, matrices of federal, state and local sources of funds, and a presentation on community organizing and consumer involvement.

The ILRU Sourcebook: A Technical Assistance Manual on Independent Living is available from the Independent Living Management Project, Independent Living Research Utilization Project, The Institute for Rehabilitation and Research, P.O. Box 20095, Houston, Texas 77025.

CURRENT INFORMATION

As stated in the beginning of the section, information sharing on program administration and operations is one objective of our conference. In scanning the literature on ILPs, I have come across only two resources that provide current information on management practices of ILPs. The only consistently updated source is the "Registry of Independent Living Programs," a computerized printout available from the Independent Living Research Utilization Project. In order to provide the reader with a thorough understanding of the data available on ILPs in the ILRU registry, a copy of the "Key to the Computerized Printout" is attached.

The second source is the forthcoming report by Peg Nosek and Justin and Yoshiko Dart, entitled, Independent Living Programs: A Management Perspective. This report is the result of a nationwide trip undertaken by the authors in 1980 at which time they visited 29 independent living programs and interviewed the top administrative staff. The report not only contains individual profiles on the 29 centers but it begins with summary of the issues addressed in the interviews combined with analyses of the administrators' responses and data collected during each visit.

Information collected on each center is summarized in profiles under the following categories:

- "Background" (how the program was started);
- "Clients" (per month and available demographic information on race, national origin, and disability);
- "Eligibility Requirements";

- "Fee Structure";
- "Office Space" (in square feet, if rented, and some brief description of the buildings)
- "Staff" (number of staff, percent disabled, percent members of minority groups);
- "Volunteers" (number of);
- "Board" (size, percent disabled and number of minority members);
- "Budget and Funding" (size of annual budget and list of funding sources);
- "Community Relations" (summary of center's activities);
- "Client Relations";
- "Advice for new Independent Living Programs" (on management issues);
- "Comments" (authors given their impressions of their visit).

This report will soon be published by the ILRU. For more information contact:

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SUMMARY OF TRENDS AND THEIR IMPLICATIONS
FOR INDEPENDENT LIVING MANAGEMENT

Compiled by: H. David Lundgren
Ian Ziskind

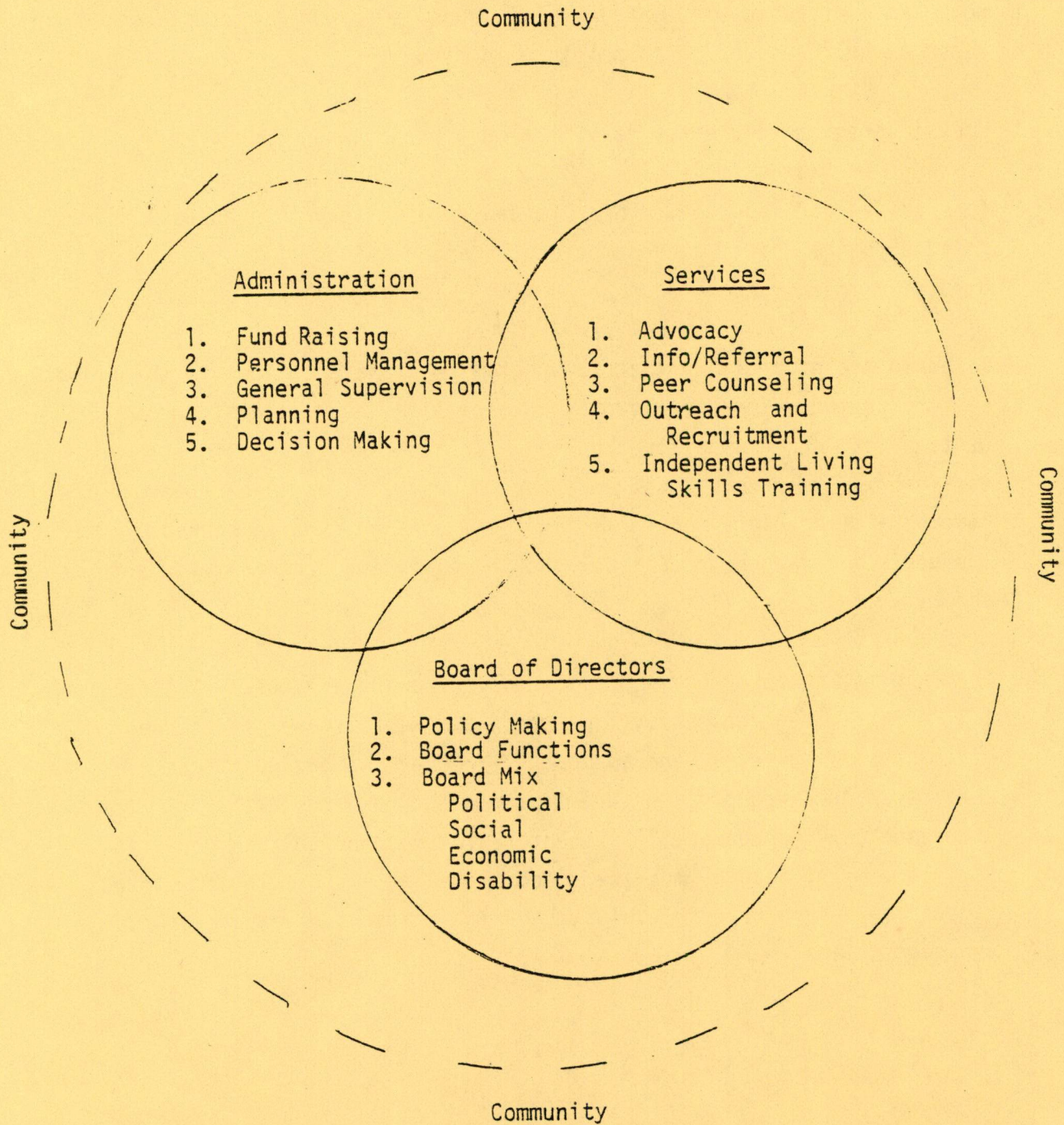
Based on research done by the Independent Living Management Project, a joint effort of the Independent Living Research Utilization (ILRU) Project at The Institute for Rehabilitation and Research, Houston, Texas and the Human Services Administration Program at Cornell University, Ithaca, New York. Work on the project was funded, in part, by a grant from the Rehabilitation Services Administration (# 629XH00031) to the Independent Living Research Utilization (ILRU) Project.

A SUMMARY OF TRENDS AND THEIR IMPLICATIONS FOR INDEPENDENT LIVING MANAGEMENT

1. Although many organizations claim to have written goals and objectives, few have measurement techniques for ascertaining their accomplishment. Therefore, there is a clear need for comprehensive data collection systems and better control between various organizational programs. A proactive rather than reactive approach to long-range planning and policy making must be adopted.
2. There exists a great deal of confusion regarding the role of the board of directors vis-a-vis the executive director. Boards must be apprised of their policy-making function and discouraged from pursuing administrative responsibilities. Therefore, board members must be trained in specific skill areas including: long-range planning, policy development, and community relations. Furthermore, board members must be made aware of the importance of a proper mix of individuals based on their qualifications, backgrounds, and disabilities. In particular, a proper balance must be struck between the social, political, and economic strengths of board members, and the need to maintain an appropriate disability representation.
3. Executive directors will need to improve their time management and delegation skills in order to enhance their staff development efforts and allow themselves more time to do long-range planning.
4. Another issue related to staff development would be the adequacy of performance appraisals. The weakness in this area stems from a poor understanding of what people do in their jobs. Because little effort has been made to clarify people's job responsibilities, job descriptions are generally of marginal quality, and staff members and administrators are consequently unclear as to what constitutes good performance. Therefore, there is a need to place more emphasis on improving job descriptions and performance appraisals. Since these organizations are labor intensive, the quality of job descriptions and performance evaluation systems will directly impact upon the selection, training, and development of staff.

5. Community relations has been approached haphazardly. Often, there are no controls over the process and little thought is given to the coordination of efforts between staff members. In addition, community relations has not been approached with a major goal such as community acceptance, consumer awareness, or fund raising in mind.
6. Most IL programs currently rely on a core of three or four primary funding sources including Title VII, I & E, Community Chest/United Way and some form of fee for services. This limited funding structure poses a risk related to the changing economic scene, and requires IL programs to diversify their funding base.
7. Based on the probability that IL programs will have to look to the private sector for future monetary support, there is a need to develop cost centers for financial accountability. In addition, a proactive approach to financial management must be taken to prevent executive directors from placing all the blame for their financial woes on funding sources. Executive directors must begin to consider the longevity and continuity of services and attempt to establish an equilibrium.
8. The majority of IL programs provide the following services: information and referral, peer counseling, outreach and recruitment, independent living skills training, and advocacy. However, as organizations grow their services often expand to include financial counseling, attendant services, attendant care management, apartment registries and/or transportation. Service diversification must be accomplished at a sensible and controlled rate. There is a need to evaluate the implications of expansion for changes in management style.

INDEPENDENT LIVING PROGRAM SYSTEMS MODEL



SUGGESTED RESOURCES

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independent living research utilization

REGISTRY
OF
INDEPENDENT LIVING PROGRAMS

KEY TO THE COMPUTERIZED PRINTOUT

Since 1978, information has been gathered on the following features of an independent living program:

(1) Type of Program:

- (a) Independent Living Center (ILC) - A community based, non-profit, non-residential program which is controlled by the disabled consumers it serves, provides directly or coordinates indirectly through referral those services which assist severely disabled individuals to increase personal self-determination and to minimize unnecessary dependence upon others. The minimum set of services that are provided by an independent living center are housing assistance, attendant care, readers and/or interpreters, peer counseling, financial and legal advocacy, and community awareness and barrier removal programs.
- (b) Independent Living Transitional Program (ILTP) - An independent living program that facilitates the movement of severely disabled people from comparatively dependent living situations to comparatively independent living situations. The primary service provided by these programs is skill training in such areas as attendant management, financial management, consumer affairs, mobility, educational-vocational opportunities, medical needs, living arrangements, social skills, time management, functional skills, sexuality, and so forth. Additional services may be provided. Transitional programs are usually goal-oriented and/or time linked. Like any independent living program, a transitional program is community-based and offers opportunities for substantial consumer involvement.

- (c) Independent Living Residential Program (ILRP) - a live-in independent living program that provides directly or coordinates through referral shared attendant services and transportation. Related services which increase personal self-determination and minimize unnecessary dependence on others may be provided. Like any independent living program, a residential program is community-based and offers opportunities for substantial consumer involvement.
- (d) Independent Living Service Provider (ILSP) - An organization which provides several discrete services which can be used to increase an individual's ability or opportunities to live independently. For example, a medical rehabilitation facility may provide out-patient services which are designed to maintain the physical health of a person who lives independently in the community. However, if the center does not provide or coordinate a full set of services including transportation, attendant care and so forth, it would be an independent living service provider rather than an independent living program. While an independent living service provider does not meet the criteria necessary to be classified as an independent living program, the services it provides may be used or coordinated by an independent living program.

(2) Disability Served:

- (a) One Type - focus on one type of disability, such as "visual impairment," or "cerebral palsy," although there may be an additional disability associated with the primary one, such as "blind-deaf."
- (b) Many - focus on more than one particular type of disability, such as "spinal cord injury" and "hearing impairment."

(3) Target Disability Type - the following is an explanation of the abbreviations used:

ADLT	Adult (persons 18 and over)
AG	Aged (persons 55 and over)
AMP	Amputation
AUT	Autism
BL	Blindness or Visual Impairment
BR.INJ.	Brain Injury
CP	Cerebral Palsy
DD	Developmental Disability
DF	Deaf or Hearing Impaired
EP	Epilepsy
MD	Muscular Dystrophy
MI	Mental Illness
MIN	Minor (persons under 18)
MR	Mental Retardation
MS	Multiple Sclerosis
ND	Neurological or Neuromuscular Disorders
POL	Polio
SCI	Spinal Cord Injury
SP.BIF.	Spina Bifida
STK/ST	Stroke

(4) Number of Persons Served Per Year:

1-25
26-50
51-150
151-500
over 500

(5) Goal Orientation:

- (a) Transitional - The program's goal is to facilitate the movement of severely disabled persons from a state of dependence to a state of independence.
- (b) Ongoing (maintenance-based) - The program aids disabled persons in maintaining maximum independence in the community where they live.

(6) Service Setting:

Residential
Non-Residential
Both (some programs have residential and non-residential components)

(7) Neighborhood:

Urban Central Business District (Urb Central Bus Dist)
Urban Residential (Urb Residential)
Suburban Residential
Rural
Campus-Style
Other

(8) Service Delivery Method:

- (a) Direct - The program's staff is primarily involved in delivery of hands-on services, such as peer counseling, independent living skills training, transportation, etc.
- (b) Indirect - The program's staff primarily provides information referral services to aid the disabled person in locating attendant care services, accessible housing, transportation, wheelchair repair companies, financial or legal counseling, and so forth.
- (c) Direct and Indirect - The program provides both direct services as well as indirect services for the disabled individual.

(9) Service Delivery Style:

- (a) Non-Handicapped (directive) - This style describes a program which is staffed primarily by persons who use a directive, prescriptive approach to working with clients.
- (b) Consumer (non-directive) - This style describes a program which is staffed primarily by persons who use an interactive, non-directive approach to working with clients.

(10) Vocational Emphasis:

- (a) Primary - Vocational goals are prerequisites for participation in the program.
- (b) Incidental - Vocational goals are not necessarily required for admission to the program, although they may be a part of a client's goals.
- (c) Nonvocational - Vocational training and counseling are not provided by the program.

(11) Services Provided:

Listed are services that the independent living program offers. Services that are primary to a program are marked by an asterisk.

Note: The information contained in the Registry is continuously being updated, and new programs and previously unsurveyed organizations are constantly being added. Double asterisks (**) before a program's name indicate that it is not currently active. Any information you can provide regarding changes in existing programs or newly established programs would be greatly appreciated. Please send this information to ILRU, P. O. Box 20095, Houston, Texas, 77025, telephone: (713) 797-1440, extension 504.

The ILRU project staff and national advisory committee developed the method of categorizing independent living programs. These are related to definitions found in "A Glossary for Independent Living," available from the ILRU project.

Accountability and Management

An Open Letter to Directors

by Maggie Shreve

As I have become more involved in the administration of Independent Living Programs, I have grown increasingly concerned about the accountability and management of our programs. This accountability is most important to consumers of our services, but is also important to current and potential funding sources. One of my favorite analogies on this subject is the relationship of Independent Living Programs to consumers. In many cases, these programs are demonstrating how to ask for help to their consumers. So, if Independent Living Programs need help with administrative issues, they also should be able to ask for help. From what I have seen over the last four years, Independent Living Programs are having difficulty doing this.

Most Independent Living Programs have similar philosophical bases but management techniques (or the lack thereof) vary widely. Of the 20 programs I have visited or with which I have worked, a majority of directors have ignored or not clearly recognized several factors which demand the attention of management: a) the limited time available for Title VII Part B grants; b) the positive impact that sound internal organization has on services provided, public relations, and the potential for funding; c) the fact that Independent Living Programs are competing with existing and traditional service providers for limited dollars; d) the need for effective communication at all levels of organization and how such communication becomes a major part of the management structure; and e) how important money is in relationship to quantity and quality of services provided.

Many program directors (and perhaps, Boards of Directors) have seemed reluctant to admit their lack of management skills and their need for help. I have attributed much of this attitude to the fear of becoming bureaucratic or too much like traditional agencies. I think this is an invalid fear and would like to point out some benefits that management has to offer Independent Living Programs.

I believe that on-the-job experience is crucial to understanding the need for management but it is not solely sufficient. Understanding the need should translate into a request for help with specific questions to be asked, per-

haps of Board members, professionals, educators, or consultants. Once a program's philosophy is set, management should be the next step in program development. The establishment of a management structure begins with a 5-step planning process:

- 1) Defining the mission — What is the program's philosophy and main effort?
- 2) Setting a goal or goals — What should happen as a result of the program's efforts in 5 years?
- 3) Listing the objectives to reach the goal(s) — How will the program address the goals during the first year, second year, etc.?
- 4) Developing action steps — How can each yearly objective be met?
- 5) Assigning responsibilities for action steps — How many and which staff or volunteers will be necessary in order to complete each action step?

Objectives should be quantifiable from top to bottom, i.e., from the Board of Directors to staff to the program's consumers. Most important, this planning process should be written down. A written plan not only helps the Board and director review progress, but also helps the entire staff understand their role(s) in the overall scheme of the program and how they contribute to meeting larger goals.

As the plan begins to take shape, a program's Board of Directors and chief executive officer (staff) should begin to address the need for management policies. Policies are simply pre-determined methods of action. They can be rigid or they can allow for great flexibility. They are developed (and written down) in order to be prepared for any eventuality. The areas where policies are needed are as follows:

- 1) Governance — Who has ultimate authority and responsibility for the program? How will the program be governed? What state or local laws must be met by the governing body? What is the relationship between the Board and the staff?
- 2) Legal — What federal, state, and local laws must be addressed by the program? What are the legal implications of the program's services? How will the

program protect itself, its board, staff, volunteers, and possibly consumers from legal actions?

- 3) Personnel — Who has the authority to hire staff? How will staff be trained and supervised? What benefits will be available to staff?
- 4) Fiscal — Who manages the program's money? How many staff or board members have access to records and cash? How does the program intend to reach financial stability? What methods of accounting are used and are these methods adequate for a certified audit?
- 5) Program — What services will be offered, by whom, and to whom? How will services be monitored for quality? What procedures are needed to insure equitable services to all eligible individuals?
- 6) Office — What are the day-to-day operating procedures in the program's physical office space? How will clerical work be delegated? Should clerical priorities be set?
- 7) Evaluation — How will goals and objectives of the program be measured and by whom? What method(s) will be used to review the effectiveness of services provided, policies, and procedures?
- 8) Optionals — Other policies may include outreach,

public relations, volunteer programming, fees for services, etc. Questions similar to those above should be asked before determining the need for desire for policies on these optional subjects.

As I struggle with all of these issues, I know that other program directors struggle also. My purpose here is to urge other administrators to ask for help when it is needed and to carefully examine what help will be given by those the program asks. Irrelevant advice can always be disregarded if it does not fit the program's philosophy or needs. Effective management allows for efficiency and flexibility. I believe it is a must if the program is to survive and provide quality services to disabled individuals. The ultimate question yet to be answered is "What will happen to the program when the mission is fulfilled?" Only thorough planning and thinking, i.e., effective management, will help Independent Living Programs find that answer.

Address: Maggie Shreve, Project Director, The Whole Person Center for Independent Living, 9805 Pennsylvania Avenue, Kansas City, Missouri 64114. Maggie is writing a management manual. If you'd like a copy, write to her and ask to be advised when it is published.

Innovations

Adaptive Equipment Center/David Tyrey

Opportunities Unlimited, Independent Living Center of Mid-Missouri, Inc. was funded in the fall of 1981 as a referral and information agency which will eventually expand to include an eight-county area.

One important aspect of Opportunities Unlimited's service delivery system will be providing assistance to disabled children and adults in the selection of necessary adaptive equipment. The center will stock a large assortment of various types of adaptive devices, which will be solicited from manufacturers and providers as sales demonstrators. Participants will then, with the consultation of the Adaptive Equipment Coordinator, be able to evaluate the effectiveness of a piece of equipment and select necessary modifications before purchasing the item directly from the supplier.

The Division of Special Education of the State of Missouri is strongly in support of the component and has pledged its financial, as well as staff support. The Division will provide the salary of the Adaptive Equipment Coordinator and other expenses of this component.

Strong support has been pledged by a number of departments of the University of Missouri. Members of these departments interacted to form a task force in 1979-80 to establish a similar adaptive equipment center. This project

was not funded by the State of Missouri, but the members of the task force have pledged their support of Opportunities Unlimited's program on an informal basis.

Opportunities Unlimited will establish fee-for-service arrangements with school districts throughout the state, and this component will contribute to the economic viability of the center independent of Title VII funds.

This component could also be expanded to include a wheelchair repair service, pending negotiations with the Electrical Engineering Department of the University of Missouri-Columbia, which currently provides this service. This will provide an additional income-producing activity for the center.

Opportunities Unlimited will provide a much needed service and provide a much needed closure of gaps in service for severely disabled individuals in the mid-Missouri area. In addition, the Adaptive Equipment component will provide a greatly needed benefit to the school age children of the entire state of Missouri.

Address: Dave Tyrey, Director, Opportunities Unlimited, Independent Living Center in Mid-Missouri, Inc., 111 South 9th Street, Suite 211, Columbia, Missouri 65201.

The Free University/Barbara G. Hummel

"Where can I find a good place to get my wheelchair fixed? And what parts of it could I fix myself?"

"How did you adapt your kitchen so you could cook?"

II. EVALUATION

ISSUE: THE CRITICAL NEED FOR PROGRAM EVALUATION OF ILPS CAN BE BEST UNDERSTOOD IN LIGHT OF TODAY'S ENVIRONMENT: THE CURRENT ADMINISTRATION HAS DE-EMPHASIZED THE FEDERAL ROLE IN THE PROVISION OF HUMAN SERVICES; THE UNEMPLOYMENT RATE IS EXTREMELY HIGH, AND, THERE IS NO APPARENT END TO THE ECONOMIC RECESSION. CRITICAL CHOICES HAVE TO BE MADE BY FEDERAL AND STATE ADMINISTRATORS RESPONSIBLE FOR DISTRIBUTING THE LIMITED HUMAN SERVICES DOLLAR. IN ORDER TO COMPETE EFFECTIVELY, A HUMAN SERVICES PROGRAM HAS TO BE ABLE TO ACCOUNT FOR ITS PAST EXPENDITURE OF PUBLIC MONIES, AND HAS TO BE ABLE TO DOCUMENT THE IMPACT OF ITS SERVICES ON THE TARGET POPULATION. SUCH INFORMATION IS LACKING IN A CONSISTENT MANNER ON THE INDEPENDENT LIVING PROGRAM NATIONWIDE. ONE REASON FOR THIS IS THE LACK OF A PRACTICAL EVALUATION TOOL TO MEASURE PROGRAM EFFECTIVENESS.

It has been anticipated by members of the planning committee that a discussion on program evaluation will take place during the meeting. With this in mind, they requested a review of current evaluation literature and the highlighting of the major issues involved. The following is by no means an exhaustive review of the literature. Time and resources prohibit such an undertaking.

Briefly, the need for program evaluation was underscored in all the readings and in subsequent conversations I have had with program directors, and officials in State Departments of Rehabilitation and in the Federal office of RSA. However, why it is needed varied as did the recommended sophistication of the evaluation tool. In addition, there were divergent views on the use of a uniform tool by ILPs and related to this, who would design and disseminate it.

The material I read fell into two categories: (1) conference reports; and (2) papers prepared by research groups. Most of the papers were written between 1980-1982, understandably corresponding with the passage and implementation of the Title VII amendments.

REASONS GIVEN FOR NEEDING EVALUATION

--Program Level. Self evaluation by ILPs has been urged for a number of reasons. First, it is a useful tool to be used by managers in determining if current program practices are accomplishing their objectives. This type of information permits managers to make refinements in service delivery methods, and a reallocation of their resources in an informed manner. In addition to the value evaluation has for program operations, it is also available as a tool for (1) legitimizing the program's existence within the community, (2) documenting their use of funds and their need for continued support, and (3) providing policymakers and advocates at the local, state and federal levels with the kind of information that is needed to support the continuation, development, and financing of favorable legislation. One major identifiable characteristic of ILPs is the role disabled people have in the formation, policymaking, and administration of the programs. Evaluations of IL services by consumers should go hand-in-hand with this philosophy as it provides another avenue for consumer input in the design and delivery of services.

--State. Statewide evaluation of ILPs has been urged not only for monitoring, accountability, and reporting reasons but also for identifying common needs for technical assistance, and for identifying gaps in services and people served in the state, thereby providing information to reshape future policy and funding priorities.

--National Office, RSA. To fulfill its responsibility to report to Congress annually on the status of IL programs, the national office has to know how many people were served, who they were, and what happened with the money.¹ Also it would be helpful for the staff of the national office as well as advocates to have documented information on cost-benefit comparisons between ILP service delivery models and more traditional service modes as a means to provide information about the importance of Title VII to severely disabled people and the American taxpayer.

EVALUATION DESIGN

The design of the evaluation tool will depend on the information needs of the evaluator. Thus, in examining the various reasons for evaluation we see that the focus, sophistication, and depth of questioning will differ depending on who is asking the questions and why. The three components most often included in evaluations are: (1) demographic and

disability information on the people served; (2) services being provided, and their cost; (3) effectiveness of the services, measured by consumer progress/improvement. Three other areas also often mentioned in the literature are: (1) consumer satisfaction with the program and its services; (2) participation of disabled people in the policymaking and administration of the program; and (3) the impact the ILP has on the community.

Of these six areas, consumer improvement seems to be the predominant focus of current research. This is understandable since evaluation tools developed to measure outcome benefits for other rehabilitation programs are not considered suitable for assessing the effect IL services has on the consumer. Unlike vocational rehabilitation which has a centralized goal (employment) that can be used with cost data as a standard for evaluation, the goal of IL differs for each individual based on their needs and desires in light of services available at the center and in the community.²

Recommended methods to evaluate consumer outcomes vary greatly in sophistication. Ted Muzzio, writing in Implementing Independent Living Centers, recommends that administrators keep the evaluation instrument as simple and basic as possible, limiting questions to those that satisfy the information needs of the manager.³ Using an individualized service plan (IWILP) as a measure of improvement, matching written goals and timetables with actual progress, has been suggested in two of the reports reviewed.⁴ Activity measures, such as Activities of Daily Living (ADL), or social activity can also be used by program staff if questionnaires are administered to consumers at entry to the program and then compared to the results of periodic ministrations. In addition to more sophisticated functional assessments, psychosocial, medical, environmental ones have also been developed. Yet there does not seem to be general agreement on the number of categories or extent of questioning that is sufficient to measure a participant's progress. James Budd, Director of Research and Training Center for Independent Living at the University of Kansas, is currently attempting to get consensus from the field on valid and reliable measures for consumer improvement that are also economical. For a review of consumer assessment techniques see: Strategies for Evaluating Independent Living Programs; Implementation of Independent Living Programs in Rehabilitation; Independent Living Program Evaluation: Issues and Beginning Alternatives; and, Measuring and Valuing Independent Living Impact: A Methodological Review.

One suggestion made by Urban Institute Researchers is that ILPs develop a two-stage approach to client evaluation. The first stage would be a simple, short range, data collection system which would meet the program's minimum information needs and reporting requirements. In this first phase they suggest inclusion of three components: "(1) the client data form used by vocational rehabilitation agencies (RSA 300); (2) basic functional ability information; (3) information on progressive diseases and sensory limitations."⁵ The second stage would be the development of a more comprehensive evaluation tool that could be tested and changed over the years. This, they suggest, would include additional functional measurements of the individual which would be given to a sample of the program participants in order to avoid draining the center's resources.⁶

DILEMMA

One problem facing a national assessment of Title VII programs may be an unanticipated problem for the new wave of decentralized programs promoted under New Federalism. Title VII permits, if not encourages, flexibility in the design of ILPs so that they meet the particular needs of their community. As a result services and their delivery methods vary as does the organization and administration of the program.

Thus it is argued, using a standardized evaluation instrument may not be feasible.⁷ Yet the needs for such national data remains. Decisionmakers today are faced with competing demands for the limited human services dollar. Sound evaluation data demonstrating the value of IL is needed as ammunition for lobbyists and state and federal officials in order to keep IL a competitive program. In Independent Living Rehabilitation: Lessons from Five Demonstration Projects, it is also argued that a common reporting evaluation system is needed so people involved in IL can take advantage of, and learn from, the variety of service delivery experiments and methods currently in practice. To do this, comparable data is needed so that programs can be compared and organizational and operational methods judged.⁸

CURRENT PRACTICE

--Program Level. In Report of the Sturbridge Conference on Independent Living Services, a concern was voiced that national evaluation guidelines be developed quickly in response to political pressures. Participants felt that this top down effort would be misdirected, and that leadership for program evaluation should come from the bottom up instead, using evaluation methods developed by programs as the building block for national guidelines.⁹

A noticeable gap in the reviewed literature is information on individual programs' evaluation techniques. This leaves the reader with the impresssion that there is not much being done at the program level and that strong leadership in this areas is lacking. The only exception was in the Evaluability Assessment of the Title VII Independent Living Program. Writers of this report indicated that in the nine centers surveyed, procedures for documenting services and the participants served, were consistently in place. They also stated, however, that the kind of information gathered differed from Center to Center. They thought this was due to a large extent to the lack of overall federal standards for data collection.¹⁰ In the report they did emphasize the need for federal guidelines. As in the Sturbridge report, they strongly recommended that the Federal office, in the development of these guidelines, turn to the Centers for guidance and example.¹¹

There is some indication in the literature that interest in program evaluation by program directors is growing. The Sturbridge conference for Federal Regions I and II was held in October 1980. The conference was structured so that invitees could select the topic area they wanted to participate in during the two day meeting. This was accomplished through a ranking system. Invitees were asked to rank their first three preferences from a list of seven topic areas. "Evaluation and Accountability" was one of the topics listed. It is reported that no participant from an ILP chose this workshop.¹² Yet, barely a year and a half later, 25 executive directors from ILPs nationwide attending an Independent Living Management Training Workshop ranked the need "for a functional model of program evaluation which is relevant to the field of Independent Living" number 1 out of a self generated list of 16.¹³

--State. A number of states have implemented state wide evaluation programs. Three states worth noting here are the states of Washington, California, and New York.

The Washington State Division of Vocational Rehabilitation funds the Independent Living Evaluation Project (ILEP), which is part of the Department of Rehabilitation Medicine at the University of Washington, Seattle. The ILEP with input from ILP directors, the project's disabled consumer committee, DVR program staff, ILP literature and researchers, has designed an innovative and practical evaluation program at the heart of which is a computer. Basically, programs are asked to fill out two series of forms, one addressing the individual, and the other center administration. Then they are asked to return the completed forms to the ILEP for computer entry and analyses. In return, they receive periodic computer printouts on their program, plus statewide aggregate data. Printouts on all centers

are sent to the State Division of Vocational Rehabilitation, and thus, the ILEP acts as an intermediary between the two groups. The ILEP encourages centers to use the system for their additional information needs and it is also available to perform different types of analyses.

The ILEP has written two publications that are worth reading. The first provided a thoughtful review of the multi-level needs for evaluation, the problems associated with it, and a review of other research projects in progress.¹⁴ The second gives a clear description of the ILEP state evaluation process, plus samples of their data collection forms, and computer printouts.¹⁵

The California State Department of Rehabilitation has been working with the California Coalition of ILPs in the refinement of their statewide evaluation program that they plan to implement this year. The program has two phases. The first phase will collect data on the following items: (1) an unduplicated annual count of participants; (2) demographic information on the participants; (3) program information: (A) number of clients per service provided; and (B) number of service units (15 minutes - one service unit) spent by service provider per participant. The second phase will be an effort to collect data on participants' progress and the severity of their disabilities). A revised client gains scale questionnaire¹⁶ will be used to measure improvement while a revised Personal Capacity Questionnaire (PCQ) will be used to determine the level of disability.¹⁷ (Both these revised forms are included in the next section of this paper.)

New York State is also implementing a statewide program this year. Their evaluation system is quite comprehensive, requiring quarterly reports that cover a number of areas. These areas include: consumer satisfaction with the ILP's services; consumer progress, determined by comparing intake information on 13 status indicators with the results of similar follow up questionnaires; data on information and referral requests; demographic information on each participant that comes to the center; statistics on: the number of persons served, units of services provided (one unit - one service provided per person), and, the number of self support plans initiated. In addition to this information, they require a narrative summary on: the ILP's impact on the community; their fundraising efforts; Board activities; and, the ILP's effort to establish interorganizational links. (The N.Y.S. plan is included in the next section of this paper.)

These three states were included in this paper because they represent three current, yet different approaches to how to collect data and what data to collect in order to evaluate the ILPs in their states.

--Federal.-- According to Bob Jones (Independent Living Program Analyst, Independent Living Projects Branch, RSA), the Office of Management and Budget has not permitted RSA to disseminate an extensive evaluation questionnaire. However, in 1980 they did disseminate a 14 page draft questionnaire to RSA regional offices for their review and comment. This questionnaire, according to Bill Bean (Chief, Independent Living Projects Branch, RSA), represents the kind of concerns his staff is interested in gathering information on. (A copy of this is included in the next section of this paper.) Because of the comments from the regional offices the questionnaire was never implemented. The major criticism was that it would require too much staff time as independent living was just one of the many programs the regional staff had oversight responsibilities for.

During my conversations with Bob Jones, he suggested a working session be convened with directors or staff of ILPs, representatives from RSA's regional and national offices, representatives from State Departments of Rehabilitation, and researchers in evaluation, in order to come up with appropriate federal guidelines and methods. Because of limited resources, Mr. Jones said RSA would not have the funds available to sponsor such a meeting.

The limitations set on RSA by OMB mentioned above, is collaborated in a study funded by the Department of Education's Division of Progress Assessment, Evaluability Assessment of the Title VII Independent Living Program, conducted by the American Institute of Research (AIR). The purpose of this report was to identify the objectives that are generally agreed upon for Title VII, and then determine if these objectives are plausible and measurable. One federal objective they discussed as being implausible was the assumption by RSA that data collection and monitoring procedures be realistic in terms of the resources they require. Such procedures should provide enough information to give a clear picture of program activities, accomplishments, and problems, and to guide management decisions on resource allocation. AIR questioned this objective for two reasons: (1) the practical difficulties in developing generally acceptable forms and gaining approval for them; and (2) the need to develop generally acceptable indices of certain key concepts such as 'independence' and 'employability.'

SUMMARY

- o Everyone agrees on the need for program evaluation.
- o At this point, there is not a generally approved method to determine program effectiveness of ILP services.
- o The federal office of RSA needs evaluation data in order to fulfill its legislative responsibilities, yet, it is restricted by OMB and its limited staff and resources from implementing a national program.
- o We can look to a number of the states for leadership in this area.
- o Information on program level self-evaluation procedures, though needed, is lacking in the literature.

Having said all this, I think there is a phenomenon which has not been mentioned in this paper, but is germane to this issue, and that is the coalition-building occurring at the state level among ILPs, the formation of the National Coalition of ILPs, and our planning session. The need for information on program effectiveness, cost, programmatic and administrative innovation, plus the identification of other data for advocacy and other purposes will undoubtedly be raised in these groups. It may be that forums such as these will provide the direction and leadership in the area of program evaluation.

EXAMPLES OF EVALUATION QUESTIONS AND FORMS

While the preceding section gave a summary of the issues bouncing around IL/Evaluation circles, this section will provide some examples of evaluation questions and forms that are currently being used or are recommended by researchers. These illustrate the variety of evaluation systems in the field, and provide a reference point for people who want to enhance or change their current evaluation procedures.

- o The first series of forms are sample forms from Washington State's Independent Living Evaluation Project.

- o The second series of questionnaires are from the California State Department of Rehabilitation. These are the forms that were adapted for use in the second phase of their statewide evaluation program. The first is a shortened version of the Client Gains Scale; and the second, an adapted version of Nancy Crew's (University of Minnesota, Department of Physical Medicine and Rehabilitation) Personal Capacities Questionnaire.

- o The third section contains two State-wide Evaluation/Information Questionnaires (N.Y. and Pa.) demonstrating, once again, the different types of data currently being collected.

- o The fourth section includes the draft guidelines developed by the RSA Central office to its regional offices for review.

- o The fifth section is a copy of a "Quarterly Cost Data" Form recommended by Timothy Muzzio et al in the Urban Institute's study, Independent Living Rehabilitation: Lessons from Five Demonstration Projects.

FOOTNOTES

1. Timothy Milligan (ed), Implementing Independent Living Centers, Conference Proceedings, p. 63.
2. Peter Janero, Deborah Wilkerson, David Haley, Independent Living Program Evaluation: Issues and Beginning Alternatives, Working Paper One, pp. 9-10.
3. Timothy Milligan (ed), Op.cit., pp. 63-64
4. B. Douglas Rice (univ. sponsor), Implementation of Independent Living Programs in Rehabilitation, pp. 122-123.

Gerben DeJong, Janice Hughes, Report of the Sturbridge Conference on Independent Living Services, p. 37.
5. Timothy Muzzio, Jeffrey Koshel, Joseph LaRocca, Independent Living Rehabilitation: Lessons From Five Demonstration Projects, p. 53.
6. Ibid., pp. 52-53.
7. Gerben DeJong, Janice Hughes, Op.Cit., p. 33.
8. Timothy Muzzio et.al., pp. 50-52.
9. Gerben DeJong, et. al., Op.Cit., p. 34..
10. Peter R. Dahl, Evaluability Assessment of the Title VII Independent Living Program, p. 58.
11. Ibid., p. 79.
12. Gerben DeJong, et. al., Op.Cit., p. 33.
13. "Operating Independent Living Programs: The Five Most Critical Areas of Current Need", from material sent by Lex Frieden to participants of the ILRU National Independent Living Management Seminar, January 17-21, 1982.
14. Peter Jamero, Deborah Wilkerson, David Haley, Op.Cit.
15. Peter Jamero, Deborah Wilkerson, Stephen Weinhouse, Independent Living Program Evaluation Database Development, Working Paper Two.
16. For full discussion on the development of this questionnaire, see: Gene Hiehle, Measuring Independent Living Program Effectiveness: A Working Paper, pp. 58.
17. Based on conversations with Bridget Robins, Research Analyst, California State Department of Rehabilitation.

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- Dahl, Peter. Evaluability Assessment of the Title VII Independent Living Program. California: The American Institutes for Research, September 1981.
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- Muzzio, Timothy, Koshel, Jeffrey, LaRocca, Joseph. Independent Living Rehabilitation: Lessons from Five Demonstration Projects. Washington, D.C., The Urban Institute.
- Rice, Douglas (University Sponsor). Implementation of Independent Living Programs in Rehabilitation. Arkansas, Arkansas Rehabilitation Research and Training Center, University of Arkansas, June 1980.
- Roessler, Richard T. Strategies for Evaluating Independent Living Programs. Arkansas, Arkansas Rehabilitation Research and Training Center, University of Arkansas, October 1981.

A. SAMPLE FORMS FROM WASHINGTON STATE'S
INDEPENDENT LIVING EVALUATION PROJECT

- o Intake Questionnaire
- o Services Provided
- o Non-Intake Services
- o ILC Community Services
- o Gaps in Service Availability

These forms were copied directly from
Independent Living Program Evaluation Database
Development, Working Paper Two, June 1981.

THE FORMS

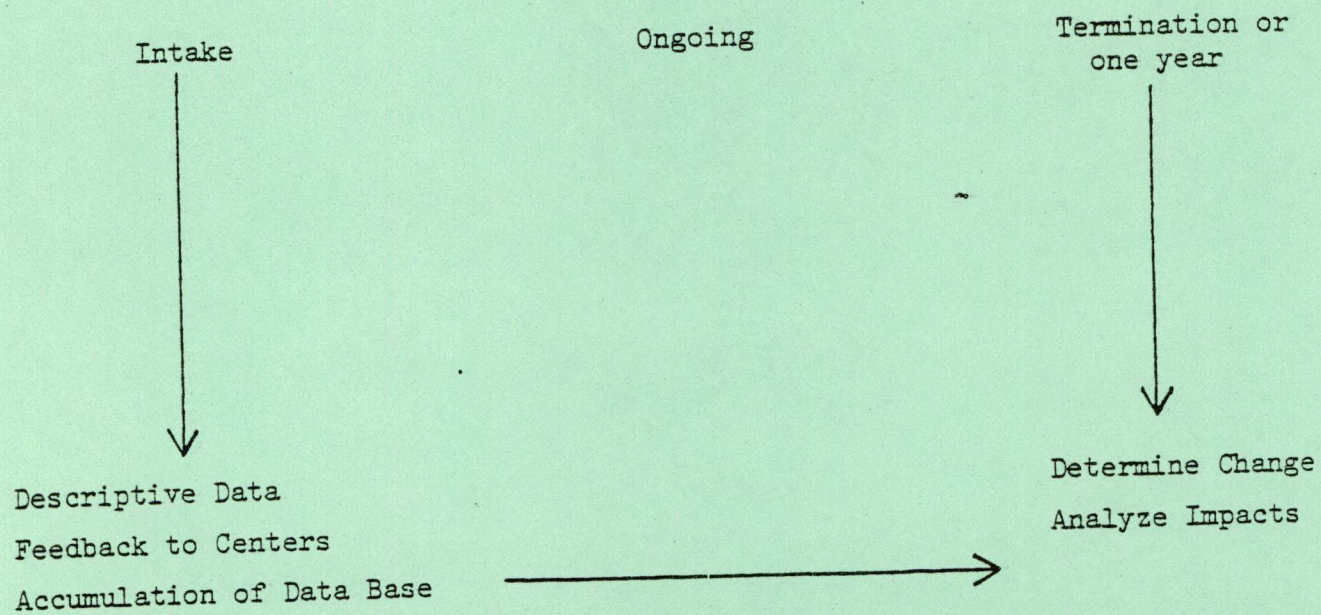
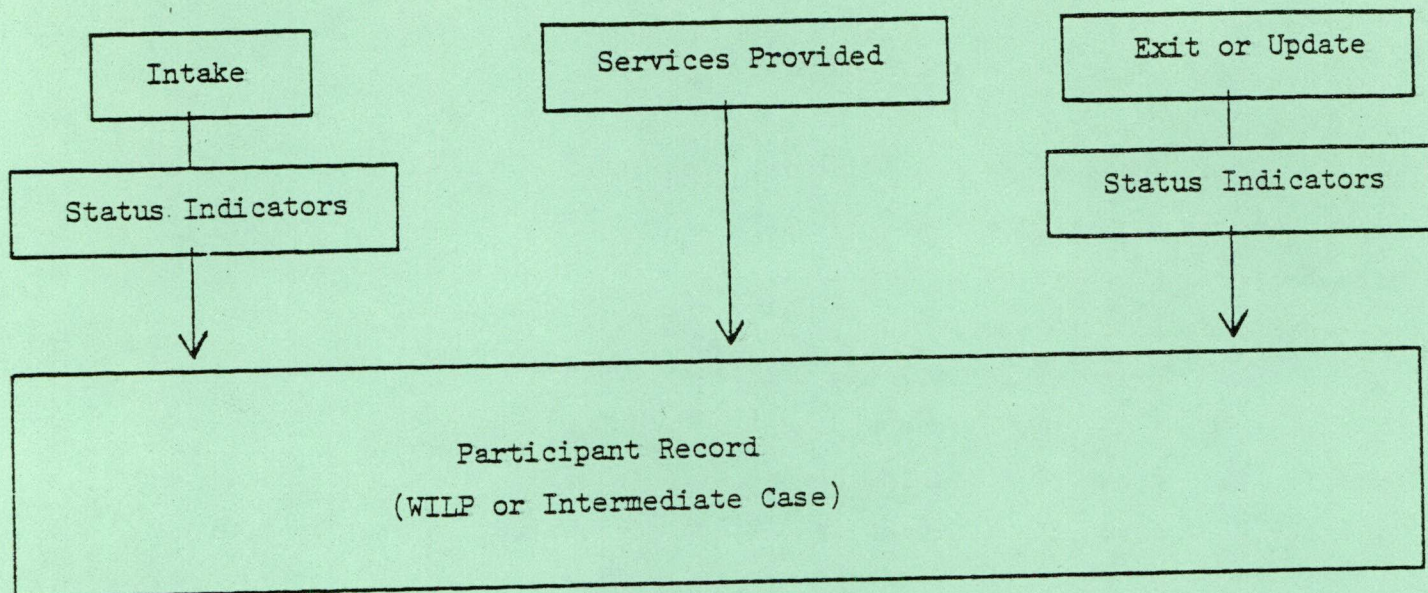
This section contains samples of the data collection forms. Most of them are printed on two or three-part NCR paper. One copy is forwarded to the Project for data entry and processing, with only the participant's ID number as identifying information. Other copies are retained in the participant's file or in a Center tickler file for follow-up purposes.

Preceding each group of forms in this section is a flow chart indicating the kinds of information included in both participant and Center data sets.

Independent Living Evaluation Project

INDEPENDENT LIVING DATA BASE

PARTICIPANT INFORMATION



Participant Number: _____

Address: _____

Phone: _____

Person to contact in the event of an emergency: Name: _____

Address: _____

Phone: _____

* PARTICIPANT ID # _____ DATE: _____ / _____ / _____ ZIP CODE _____ RURAL _____ URBAN _____

REFERRAL SOURCE: ☐ DVR OTHER: (please list) _____
REASON FOR CONTACT: _____
SPECIAL PROGRAM CODE _____

THE INFORMATION IN THE BOX IS OPTIONAL, BUT WILL HELP US IN DETERMINING FUTURE PROGRAM NEEDS.

TE OF BIRTH: _____ / _____ / _____ AGE: _____
ETHNIC ID: _____
ASIAN/ PACIFIC ISLANDER _____
HISPANIC _____
NATIVE AMERICAN OR ALASKA NATIVE _____
WHITE _____
NOT AVAILABLE _____
OTHER (please specify) _____

DISABILITY: (please list all that apply)

* DISABILITY CHARACTERISTICS: PROGRESSIVE WORSENING CONDITION YES _____ NO _____ UK _____
CHRONIC LENGTH OF TIME DISABLED YES _____ NO _____ UK _____
#yrs / months _____

* DVR CONTACT STATUS _____

* USE OF ATTENDANT CARE SERVICES YES _____ NO _____
* USE OF CHORE SERVICES YES _____ NO _____
* CURRENTLY USE INTERPRETER OR READER YES _____ NO _____

If yes, are you satisfied with the quantity of interpreter/reader services you get? _____
ALMOST ALWAYS _____ SOMETIMES _____ RARELY _____

If yes, are you satisfied with the quality of interpreter/reader services you get? _____
ALMOST ALWAYS _____ SOMETIMES _____ RARELY _____

* ADEQUATE ACCESS TO TRANSPORTATION WHEN YOU NEED IT? _____
ALMOST ALWAYS _____ SOMETIMES _____ RARELY _____

* ADEQUATE ACCESS TO TRANSPORTATION WHEN YOU WANT IT? _____
ALMOST ALWAYS _____ SOMETIMES _____ RARELY _____
DATE OF TERMINATION IF APPROPRIATE _____ / _____ / _____

SELF - CARE	
PERSONAL MOBILITY (crutches, canes, wheelchairs, dogs, etc.)	
COMMUNICATION	
TELECOMMUNICATION	
TRANSPORTATION	
PRIVATE	
PUBLIC	
HOME MODIFICATION	
STRUCTURAL	
EQUIPMENT	
RECREATION/ATHLETICS	
EDUCATION	
EQUIPMENT	
STRUCTURAL	
JOB MODIFICATION	
STRUCTURAL	
EQUIPMENT	
OTHERS (please list)	
WOM USE	
WOULD USE IF AVAILABLE	
THERE MUST BE A BETTER WAY, BUT I DON'T KNOW WHAT	
N/A	

*CURRENT ASSISTIVE DEVICE USE IN:

DEPENDENT LIVING EVALUATION PROJECT

SERVICES PROVIDED

ID #

CODE LIST	DATE	SERVICE CODE select from code list	 UNIVERSITY OF WASHINGTON INDEPENDENT LIVING	TIME
<u>0 ADVOCACY</u>				
012 Assertiveness, advocacy training				
014 Provision of advocacy services				
<u>10 ASSESSMENT AND EVALUATION</u>				
021 Referral				
024 Provision				
<u>30 ATTENDANT, HOMEMAKER, CHORE</u>				
031 Assistance in locating PCA, chore				
032 Training in attendant management				
034 Provision				
<u>40 CASE PLANNING AND COORDINATION</u>				
041 Assistance and referral				
044 Provision				
<u>50 COMMUNICATIONS</u>				
051 Interpreter referral				
052 Communication skills training including sign language				
053 Equipment, incl. TTY, TDD, brailers				
054 Provision - interpreters, readers				
<u>60 COUNSELING</u>				
<u>070 Peer Counseling</u>				
071 Referral				
072 Training				
074 Provision				
<u>080 Vocational Counseling</u>				
081 Referral				
084 Provision				
<u>090 Family and Other</u>				
091 Referral				
094 Provision				
<u>10 EDUCATION</u>				
101 Referral, assistance in locating schooling				
104 Provision of schooling, i.e., subject matter				
<u>10 FINANCIAL, INCOME SUPPORT</u>				
111 Referral, assistance in locating				
112 Training in financial skills				
<u>20 HOUSING</u>				
121 Assistance in locating				
123 Housing modification, barrier removal				
124 Provision of housing services				
<u>30 INDEPENDENT LIVING SKILLS</u>				
<u>140 Child Care</u>				
141 Referral				
142 Training				
143 Equipment				
<u>150 Cognition</u>				
151 Remembering and orienting referral				
152 Remembering and orienting training				
153 Remembering and orienting equipment				
<u>160 Community Resource Access Skills</u>				
161 Referral				
162 Training				
<u>170 Homemaking, Shopping, Meal Preparation</u>				
171 Referral				
172 Training				
173 Equipment				
<u>180 Personal Care</u>				
181 Referral				
182 Training				
183 Equipment				
<u>190 Problem Solving and Decision Making</u>				
191 Referral				
192 Training				
<u>200 Socialization and Self Image</u>				
201 Referral				
202 Training				
<u>210 Time Management</u>				
211 Referral				
212 Training				
213 Equipment				
<u>30 LEGAL RIGHTS</u>				
301 Referral, assistance, information				
302 Legal rights training				
304 Provision of legal services				
<u>40 MEDICAL/HEALTH</u>				
311 Referral/coordination - medical/health				
312 Medical/Health maintenance training				
314 Provision of medical/health services				
<u>50 PERSONAL MOBILITY</u>				
322 Personal mobility training				
323 Personal mobility equipment				
<u>60 RECREATION</u>				
331 Referral, assistance in locating services				
332 Recreational skills training				
333 Recreational equipment				
334 Provision of recreational services				
<u>40 THERAPY/MENTAL HEALTH SERVICES</u>				
341 Referral and assistance				
344 Provision of mental health services				
<u>50 TRANSPORTATION</u>				
351 Referral, assistance in locating				
352 Transportation use training				
353 Transportation equipment(e.g., vehicle mod.)				
354 Provision of transportation				
<u>60 VOCATIONAL EVALUATION</u>				
361 Referral for vocational evaluation				
363 Equipment (e.g., job site modification)				
364 Provision of vocational evaluation				
<u>00 OTHER</u>				

Independent Living Evaluation Project

INDEPENDENT LIVING DATA BASE

CENTER INFORMATION

Form

Non-Intake Services

Community Service
Activities

Service
Gaps

Informa-
tion
C ured

Short-term Individual

Group-oriented Services

Need for Services

Quantita-
tive Value

Adds to "Number Served"

Staff Hours of Service
to Community

Number of Partici-
pants in Need;
Number of Needs

Name: _____ Date: _____

Address: _____ Phone: _____

Referral Source: _____

Problem: _____

Solution/Referral: _____

General Comments: _____

Followup Date: _____ Completed: Yes _____ No _____

(This section is to be torn off and returned to ILEP)

TYPE OF NEED

AREA OF NEED

- | | |
|---|---|
| 1 ☐ Information only | 1 ☐ Accessibility |
| 2 ☐ Aid/assistance | 2 ☐ ADL, IL skills |
| 3 ☐ Advocacy | 3 ☐ Child Care |
| | 4 ☐ Communication or Interpreting |
| | 5 ☐ Counseling |
| | 6 ☐ Education, training |
| | 7 ☐ Equipment |
| | 8 ☐ Financial, Income support |
| | 9 ☐ Health Care and Medical Services |
| | 10 ☐ Housing |
| | 11 ☐ Legal Problems |
| | 12 ☐ PCA, Chore services, training |
| | 13 ☐ Personal Mobility |
| | 14 ☐ Program Services (Ctr. Information) |
| | 15 ☐ Recreational, Social needs |
| | 16 ☐ Rights and Responsibilities |
| | 17 ☐ Sexuality |
| | 18 ☐ Transportation |
| | 19 ☐ Vocational, business, employment |
| | 20 ☐ Community Resources (Other than those listed above) |
| | 21 ☐ Other (Please List) |

OUTCOME

- 1 ☐ Completed (in house)
- 2 ☐ Referred to any-one outside of IL Program.
- 3 ☐ Couldn't complete (transfer need to gaps form if appropriate).

TIME (OPTIONAL)

____ hrs. ____ min.

Name: _____ Date: _____

Address: _____ Phone: _____

Referral Source: _____

Problem: _____

Solution/Referral: _____

General Comments: _____

Followup Date: _____ Completed: Yes _____ No _____

(This section is to be torn off and returned to ILEP)

TYPE OF NEED

AREA OF NEED

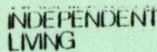
- | | |
|---|---|
| 1 ☐ Information only | 1 ☐ Accessibility |
| 2 ☐ Aid/assistance | 2 ☐ ADL, IL skills |
| 3 ☐ Advocacy | 3 ☐ Child Care |
| | 4 ☐ Communication or Interpreting |
| | 5 ☐ Counseling |
| | 6 ☐ Education, training |
| | 7 ☐ Equipment |
| | 8 ☐ Financial, Income support |
| | 9 ☐ Health Care and Medical Services |
| | 10 ☐ Housing |
| | 11 ☐ Legal Problems |
| | 12 ☐ PCA, Chore services, training |
| | 13 ☐ Personal Mobility |
| | 14 ☐ Program Services (Ctr. Information) |
| | 15 ☐ Recreational, Social needs |
| | 16 ☐ Rights and Responsibilities |
| | 17 ☐ Sexuality |
| | 18 ☐ Transportation |
| | 19 ☐ Vocational, business, employment |
| | 20 ☐ Community Resources (Other than those listed above) |
| | 21 ☐ Other (Please List) |

OUTCOME

- 1 ☐ Completed (in house)
- 2 ☐ Referred to any-one outside of IL Program.
- 3 ☐ Couldn't complete (transfer need to gaps form if appropriate).

TIME (OPTIONAL)

____ hrs. ____ min.



Independent Living Evaluation Project
P. Jamero, D. Wilkerson, S. Weinhouse

B. TWO REVISED FORMS FROM THE CALIFORNIA STATE
DEPARTMENT OF REHABILITATION

- o Shortened Version of the
Client Gains Scale
- o Revised Personal Capacities Questionnaire

The Client Gains Scale was taken directly from
Measuring Independent Living Program Effectiveness,
A Working Paper by Gene Hiehle.

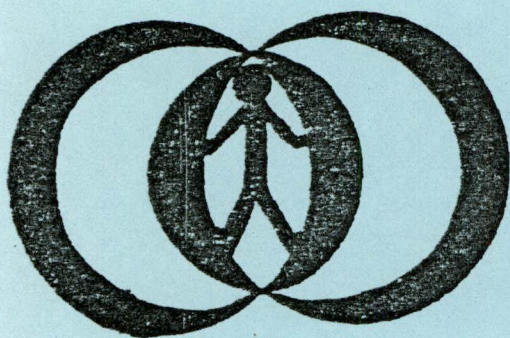
APPENDIX C: SHORTENED VERSION OF THE
CLIENT GAINS SCALE

CALIFORNIA

INDEPENDENT

LIVING

SURVEY



INSTRUCTIONS

The attached questionnaire deals with various aspects of your life. Some of the answers may not describe your present situation or feelings exactly, but please mark each question with the answer which fits you best.

PLEASE GO TO THE NEXT PAGE

SECTION E - YOUR HEALTH

During the last six months about how many times have you seen a medical doctor for routine medical care? (CHECK ONLY ONE)

- ☐ 16 or more
- ☐ 11 to 15
- ☐ 6 to 10
- ☐ 1 to 5
- ☐ none

During the last six months how many separate times have you stayed in a hospital or used emergency medical care? (CHECK ONLY ONE)

- ☐ none
- ☐ 1 or 2
- ☐ 3 or 4
- ☐ 5 or 6
- ☐ 7 or more

How many different drugs (including prescription and non-prescription) do you take as pain killers, tranquilizers, or sedatives? (CHECK ONLY ONE)

- ☐ 5 or more
- ☐ 3 or 4
- ☐ 1 or 2
- ☐ none

Aside from your disability, how would you describe your general physical health? (CHECK ONLY ONE)

- ☐ Excellent
- ☐ Good
- ☐ Fair
- ☐ Poor

5. About how many hours a week do you spend in physical activity (including physical therapy)? (CHECK ONLY ONE)

- ☐ none
- ☐ 1 to 5 hours
- ☐ 6 to 10 hours
- ☐ 11 to 15 hours
- ☐ more than 15 hours

 SECTION F - YOUR SOCIAL LIFE AND YOUR FEELINGS ABOUT YOURSELF

1. How many people in your life do you consider to be close friends?
(CHECK ONLY ONE)
- ☐ 0 or 1
- ☐ 2 or 3
- ☐ 4 or 5
- ☐ 6 or 7
- ☐ 8 or more
2. How many of these close friends do you have contact with at least once a month? (CHECK ONLY ONE)
- ☐ 0 or 1
- ☐ 2 or 3
- ☐ 4 or 5
- ☐ 6 or 7
- ☐ 8 or more
3. Which of the following kinds of groups or organizations do you belong to, and how active are you? (CHECK ALL THAT APPLY)

IF YOU BELONG,
How often do you take part?

DO YOU BELONG?

Often Sometimes Rarely

- | | | | | | | |
|--|-----------------------------|------------------------------|---|--------------------------|--------------------------|--------------------------|
| • Social/recreational group | ☐ No | ☐ Yes | → | ☐ | ☐ | ☐ |
| • Organization of or for disabled people | ☐ No | ☐ Yes | → | ☐ | ☐ | ☐ |
| • Political action organizations | ☐ No | ☐ Yes | → | ☐ | ☐ | ☐ |
| • Groups concerned with community issues | ☐ No | ☐ Yes | → | ☐ | ☐ | ☐ |
| • Professional or work-related groups | ☐ No | ☐ Yes | → | ☐ | ☐ | ☐ |
| • Church or religious groups | ☐ No | ☐ Yes | → | ☐ | ☐ | ☐ |
| • Other (please list) | ☐ No | ☐ Yes | → | ☐ | ☐ | ☐ |

SECTION F - YOUR SOCIAL LIFE AND YOUR FEELINGS ABOUT YOURSELF (continued)

4. How would you describe your present emotional well-being?
(CHECK ONLY ONE)

- ☐ Excellent
☐ Good
☐ Fair
☐ Poor
☐ Don't know

5. Please check all of the following activities that you take part in regularly.

- ☐ Reading - magazines, books, newspapers, etc.
☐ Hobbies - stamp collecting, model building, coin collecting, inventing, repair work for amusement, photography, etc.
☐ Crafts - sewing, leatherwork, woodwork, refinishing furniture, etc.
☐ Arts - playing music, acting, drawing, painting, creative writing, etc.
☐ Games - chess, cards, backgammon, etc.
☐ Outdoor Activities - fishing, hunting, camping, rafting, hiking, etc.
☐ Physical Activities - swimming, basketball, bowling, racing, dancing, etc.
☐ Other Activities (describe) _____

PLEASE INDICATE HOW MUCH YOU AGREE OR DISAGREE WITH THE FOLLOWING STATEMENTS BY CHECKING ONE OF THE BOXES TO THE RIGHT OF EACH STATEMENT.

	Strongly agree	Agree somewhat	Uncertain	Disagree somewhat	Strongly disagree
6. I take good care of myself physically.	☐	☐	☐	☐	☐
7. I am satisfied to be just what I am.	☐	☐	☐	☐	☐
8. I solve my problems easily.	☐	☐	☐	☐	☐
9. I am as sociable as I want to be.	☐	☐	☐	☐	☐
10. I feel that people almost always treat me right.	☐	☐	☐	☐	☐
	Strongly agree	Agree somewhat	Uncertain	Disagree somewhat	Strongly disagree

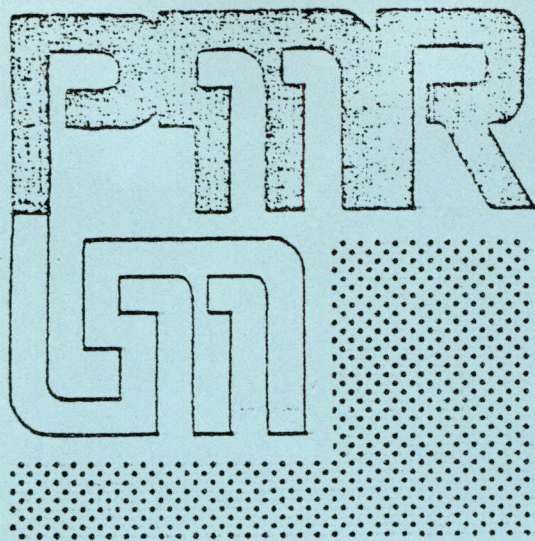
SECTION F - YOUR SOCIAL LIFE AND YOUR FEELINGS ABOUT YOURSELF (continued)

	Strongly agree	Agree somewhat	Uncertain	Disagree somewhat	Strongly disagree
11. I find it easy to start a conversation with a stranger.	☐	☐	☐	☐	☐
12. I always feel that I can accomplish the things I want to do.	☐	☐	☐	☐	☐
13. I like to take on new and important responsibilities such as organizing people.	☐	☐	☐	☐	☐
14. I become nervous and tense when competing with other people.	☐	☐	☐	☐	☐
15. I start work on a new project with a great deal of enthusiasm.	☐	☐	☐	☐	☐
16. I am usually confident of my abilities	☐	☐	☐	☐	☐
17. My friends seem to have a better time than I do.	☐	☐	☐	☐	☐
	Strongly agree	Agree somewhat	Uncertain	Disagree somewhat	Strongly disagree

INSTRUCTIONS FOR MAILING

Thank you for completing this questionnaire. We want your answers to count, so please be sure you have answered all the questions. Return the questionnaire in the envelope provided. It should be addressed to:

Independent Living Research Study
P. O. Box 428
Broderick, CA 95605



PERSONAL CAPACITIES QUESTIONNAIRE *

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DIRECTIONS

THE PURPOSE OF THIS QUESTIONNAIRE IS TO FIND OUT WHAT YOUR STRENGTHS AND WEAKNESSES ARE. THIS INFORMATION WILL HELP US TO UNDERSTAND HOW WELL THE INDEPENDENT LIVING CENTER CAN MEET YOUR NEEDS.

FOR THE FIRST 16 QUESTIONS, YOU WILL BE ASKED TO RATE YOURSELF ON A SCALE OF 0, 1, 2, OR 3. NEXT TO THE NUMBERS IN EACH SCALE ARE SHORT STATEMENTS DESCRIBING HOW YOU WOULD ACT OR APPEAR IF YOU HAD NO LIMITATION (0), SOME (1), QUITE A BIT (2), OR A GREAT AMOUNT (3) OF LIMITATION. FOR EACH QUESTION CHOOSE THE STATEMENT THAT BEST DESCRIBES YOU. THEN MARK YOUR ANSWER BY CIRCLING THE NUMBER THAT MATCHES THAT STATEMENT. (FOR EXAMPLE, FOR QUESTION #2, IF YOU DO NOT HAVE ANY DIFFICULTY HEARING, YOU WOULD MARK YOUR ANSWER IN THE FOLLOWING WAY: 2. ☒ 1 2 3).

QUESTIONS #17 TO 22 ARE A LIST OF POSITIVE QUALITIES. PUT A CHECK MARK (✓) BY ANY OF THEM THAT APPLY TO YOU. REMEMBER THAT YOUR NAME WILL NOT BE USED IN CONNECTION WITH THESE ANSWERS BUT THE RESULTS ARE IMPORTANT. PLEASE BE AS ACCURATE AS POSSIBLE.

*Revised by the California Department of Rehabilitation for Independent Living applications.

1. VISION (WITH EYEGASSES OR CONTACT LENSES IF YOU WEAR THEM).

- 0. I HAVE NO TROUBLE SEEING.
- 1. IT IS HARD FOR ME TO SEE SMALL PRINT.
- 2. I CANNOT DO SOME IMPORTANT ACTIVITIES (FOR EXAMPLE, READING OR DRIVING) BECAUSE I CANNOT SEE WELL ENOUGH.
- 3. I HAVE LITTLE OR NO VISION.

2. HEARING (WITH A HEARING AID IF YOU USE ONE)

- 0. I HAVE NO TROUBLE HEARING.
- 1. I SOMETIMES HAVE TROUBLE UNDERSTANDING CONVERSATIONS OR USING THE PHONE.
- 2. MY HEARING IS SO POOR THAT I CANNOT USE THE TELEPHONE.
- 3. I CANNOT HEAR CONVERSATION WELL ENOUGH TO UNDERSTAND IT.

3. ABILITY TO GET AROUND

- 0. I AM ABLE TO WALK WITHOUT DIFFICULTY.
- 1. I HAVE SOME DIFFICULTY GETTING AROUND. (FOR EXAMPLE, YOU DO NOT USE A WHEELCHAIR BUT FIND IT HARD TO WALK EITHER AS FAST OR AS LONG AS MOST PEOPLE; OR YOU USE A WHEELCHAIR AND CAN OPERATE AND MOVE IN AND OUT OF IT WITHOUT HELP FROM OTHER PEOPLE; OR YOU HAVE A VISUAL IMPAIRMENT THAT HAS SOME EFFECT ON YOUR ABILITY TO GET AROUND, BUT YOU ARE ABLE TO GO WHEREVER YOU NEED TO WITHOUT HELP FROM OTHER PEOPLE.)
- 2. I HAVE QUITE A BIT OF DIFFICULTY GETTING AROUND. (FOR EXAMPLE, YOU DO NOT USE A WHEELCHAIR BUT CAN WALK ONLY FOR VERY SHORT DISTANCES OVER FLAT SURFACES; OR YOU USE A WHEELCHAIR AND CAN TRAVEL IN IT FOR AT LEAST A BLOCK WITHOUT HELP FROM OTHERS, BUT YOU NEED HELP TO MOVE IN AND OUT OF IT; OR YOU HAVE A VISUAL IMPAIRMENT THAT SOMETIMES REQUIRES YOU TO HAVE HELP FROM OTHERS IN ORDER TO GET FROM PLACE TO PLACE.)

3. I MUST HAVE THE HELP OF OTHER PEOPLE TO GET AROUND. (FOR EXAMPLE, YOU USE A WHEELCHAIR AND NEED HELP IN ORDER TO TRAVEL MORE THAN A BLOCK; OR YOU HAVE A VISUAL IMPAIRMENT AND NEED HELP IN GETTING AROUND WHENEVER YOU ARE AWAY FROM HOME.)

4. USE OF ARMS

0. BOTH OF MY ARMS WORK NORMALLY.
1. MY PREFERRED ARM (MY RIGHT IF I AM RIGHT-HANDED OR MY LEFT IF I AM LEFT-HANDED) WORKS WELL, BUT THE OTHER DOES NOT.
2. BOTH OF MY ARMS ARE A LITTLE LIMITED IN HOW WELL THEY WORK.
OR
MY PREFERRED ARM DOES NOT WORK WELL, BUT THE OTHER IS OKAY.
3. I HAVE LITTLE OR NO USE OF EITHER OF MY ARMS.

5. USE OF HANDS

0. BOTH OF MY HANDS WORK NORMALLY.
1. MY HANDS ARE A LITTLE CLUMSY OR SLOW.
2. USE OF MY HANDS IS QUITE LIMITED, BUT (WITH OR WITHOUT AIDS OR DEVICES) I CAN WRITE, FEED MYSELF, AND DO MOST OR ALL ORDINARY SELF-CARE TASKS.
3. MY HANDS WORK SO POORLY THAT I CANNOT DO MY OWN SELF-CARE.

6. COORDINATION

0. MY COORDINATION IS AS GOOD AS MOST PEOPLE'S.
1. I TEND TO BE SOMEWHAT UNCOORDINATED.
2. MY COORDINATION IS MUCH POORER THAN MOST PEOPLE'S.
3. I AM UNABLE TO CONTROL MY MOVEMENTS AND TO DO THINGS SMOOTHLY.

7. SPEED

- 0. I MOVE AS QUICKLY AS MOST PEOPLE.
- 1. I MOVE A LITTLE MORE SLOWLY THAN MOST PEOPLE.
- 2. I MOVE QUITE SLOWLY. JOBS THAT REQUIRE SPEED (FOR EXAMPLE, KEEPING UP WITH AN ASSEMBLY LINE) WOULD NOT BE SUITABLE FOR ME.
- 3. I MOVE VERY SLOWLY.

8. STABILITY OF CONDITION

- 0. MY DISABILITY IS STABLE. (IN OTHER WORDS, IT WILL NOT BECOME WORSE.)
 - 1. MY DISABILITY COULD BECOME WORSE UNLESS I KEEP IT UNDER CONTROL WITH DIET, TREATMENT, OR EXERCISE.
 - 2. MY DISABILITY IS SLOWLY GETTING WORSE.
- OR
- IT IS HARD TO PREDICT HOW MY DISABILITY WILL CHANGE. IT COULD STAY THE SAME, OR IT MIGHT GET QUITE A BIT WORSE.
- 3. MY DISABILITY IS LIKELY TO BECOME MUCH WORSE IN THE FUTURE.

9. LEARNING ABILITY

- 0. I LEARN JUST AS FAST AS OTHER PEOPLE.
- 1. I CAN LEARN DIFFICULT THINGS, BUT I NEED EXTRA TIME.
- 2. IN SCHOOL I WAS IN SPECIAL CLASSES FOR STUDENTS WHO NEEDED EXTRA HELP.
- 3. LEARNING IS VERY HARD FOR ME. I NEED EXTRA TIME AND HELP TO LEARN MOST NEW THINGS.

10. PERCEPTION

- 0. WHEN I LOOK AT THINGS, THEY NEVER SEEM CONFUSED OR MIXED-UP.
- 1. I DON'T DO WELL AT THINGS THAT REQUIRE LOOKING CLOSELY AT DETAILS.
- 2. IT IS VERY HARD FOR ME TO FOLLOW MAPS, TO PUT TOGETHER JIGSAW PUZZLES, OR TO DO OTHER THINGS THAT REQUIRE ME TO SEE HOW THINGS FIT TOGETHER.

3. THE WORLD SEEMS CONFUSING OR MIXED-UP TO ME. I OFTEN GET LOST, EVEN IN PLACES THAT I KNOW.

11. MEMORY

0. MY MEMORY IS GOOD.
1. FORGETTING THINGS IS OFTEN A PROBLEM FOR ME.
2. MEMORY PROBLEMS OFTEN MAKE IT HARD FOR ME TO LEARN NEW THINGS. I USUALLY NEED TO HAVE DIRECTIONS AND INFORMATION REPEATED TO ME.
3. MY MEMORY IS VERY POOR. I OFTEN FEEL CONFUSED. IT IS HARD FOR ME TO REMEMBER THINGS FROM ONE DAY TO THE NEXT.

12. SPOKEN COMMUNICATION

0. I UNDERSTAND AND SPEAK ENGLISH WITHOUT ANY DIFFICULTY.
1. I HAVE SOME PROBLEM COMMUNICATING IN ENGLISH WITH OTHER PEOPLE. (IF I AM HEARING IMPAIRED, I CAN USE LIPREADING SPEECH TO COMMUNICATE.)
2. IT IS HARD FOR ME TO COMMUNICATE IN ENGLISH WITH MOST PEOPLE. I CANNOT SAY MORE THAN A FEW WORDS. (IF I AM HEARING IMPAIRED, I USE SIGN LANGUAGE BUT CANNOT COMMUNICATE THROUGH LIPREADING AND SPEECH.)
3. I CANNOT COMMUNICATE THROUGH SPOKEN ENGLISH WITH OTHER PEOPLE.

13. READING AND WRITING (IN PRINT OR IN BRAILLE)

0. I HAVE NO TROUBLE READING AND WRITING ENGLISH.
1. I HAVE A LITTLE TROUBLE READING OR WRITING ENGLISH (FOR ANY REASON; FOR EXAMPLE, LACK OF GOOD SCHOOLING OR BECAUSE THE FIRST LANGUAGE I LEARNED WAS NOT ENGLISH).
2. IT IS VERY HARD FOR ME TO READ OR WRITE ENGLISH.
3. I CANNOT READ OR WRITE ENGLISH.

14. SPEECH

- 0. I HAVE NO DIFFICULTY SPEAKING
- 1. PEOPLE CAN UNDERSTAND MY SPEECH MOST OF THE TIME, BUT IT MAY SOUND UNUSUAL.
- 2. MY SPEECH IS DIFFICULT FOR OTHER PEOPLE TO UNDERSTAND. I OFTEN HAVE TO REPEAT MYSELF.
- 3. MOST PEOPLE CANNOT UNDERSTAND MY SPEECH.

15. JUDGMENT

- 0. I ACT WISELY ALMOST ALL OF THE TIME.
- 1. I SOMETIMES MAKE THE WRONG DECISION BECAUSE I RUSH INTO THINGS WITHOUT THINKING OVER THE CHOICES.
- 2. I OFTEN GET INTO TROUBLE BECAUSE OF UNWISE DECISIONS.
- 3. I HAVE CAUSED ACCIDENTAL INJURY TO MYSELF OR SOMEONE ELSE EITHER BY DOING SOMETHING FOOLISH OR BY FORGETTING TO DO SOMETHING I SHOULD HAVE DONE.

16. PERSONAL ATTRACTIVENESS

- 0. I AM AT LEAST AS ATTRACTIVE AND WELL-GROOMED AS MOST PEOPLE.
- 1. I HAVE SOME PROBLEM WITH MY APPEARANCE OR HYGIENE, BUT PEOPLE USUALLY GET USED TO IT AND ACCEPT ME WITHOUT MUCH DIFFICULTY.
- 2. PEOPLE FIND IT HARD TO ACCEPT ME BECAUSE OF MY APPEARANCE OR GROOMING.
- 3. MOST PEOPLE AVOID ME.

SPECIAL STRENGTH ITEMS (PUT A CHECK MARK ON THE ANSWER SHEET FOR ANY THAT APPLY.)

- 17. I AM VERY GOOD LOOKING.
- 18. I HAVE A VERY PLEASING PERSONALITY.
- 19. I AM UNUSUALLY INTELLIGENT.
- 20. MY FAMILY IS EXTREMELY UNDERSTANDING AND EAGER TO HELP ME.
- 21. I HAVE NO FINANCIAL WORRIES THAT COULD INTERFERE WITH MY REHABILITATION PROGRAM.
- 22. I HAVE UNUSUALLY GOOD COMMON SENSE.

C. TWO STATE-WIDE EVALUATION QUESTIONNAIRES

- o New York
- o Pennsylvania

Introduction

Studies and evaluations of the needs of and services for severely handicapped individuals for independent living rehabilitation services were mandated by the Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments of 1978 (PL 95-602), 34CFR365.8, and the State Plan for Independent Living Services. The State Plan (Section 8) requires that evaluations be conducted periodically with the participation of consumers or, as appropriate, their representatives and providers to measure the adequacy of State unit performance in providing independent living services to severely handicapped individuals in the light of program and financial resources available in the State.

Independent Living Programs provide services which should enable severely handicapped individuals to increase their a) functional capacities and life options, b) abilities to live independently in home and community, c) potential for employment, and d) access to a barrier-free environment. Evaluation questions focus on the extent to which the Independent Living Program is accomplishing its stated objectives and individuals are experiencing gains in important life areas; e.g., physical, economic, psychosocial, and educational-vocational. These gains in personal functioning should also have a direct relationship to the level of satisfaction the individual has with the services provided. Hence, client satisfaction is another dimension appropriate for assessment of Independent Living Programs.

Although assessing both project operations and client independence, this evaluation will separate center operations from client gains resulting from program services. Described below are the components of the evaluation which have been designed to measure the extent to which the Independent Living Program is accomplishing the above objectives.

1. Reporting by the centers will be completed according to a uniform format. In addition to a narrative describing community impact, progress in fund raising, role of the Board of Directors etc., reports from the centers will include statistics on the number of persons served, the units of service provided, and the number of self support plans developed. Individuals served, units of service, and each specific service are now defined.
2. For information and referral requests, a log will be kept which records services requested and respective services provided. Callers (or visitors) will be asked if they would be willing to respond at a later date to an inquiry regarding the accuracy and adequacy of the information provided. If the caller expresses a willingness to participate a post card will be sent asking the above questions. Comments/suggestions will also be solicited. Such a log and follow up will not only provide information on those services provided but will also act as an ongoing needs assessment by recording those services frequently requested which the centers are not providing. Centers will also have the benefit of receiving anonymous suggestions from their clients.
3. The third component of the evaluation is based upon a demographic survey completed for each client who comes to the center. The data collected from this wide range of client characteristics will provide information on the populations served by each center individually as well as the Statewide Independent Living Program in its entirety.
4. The fourth component of the evaluation is actually an intake supplement consisting of 13 status indicators. Information collected through this supplement will serve as a basis against which future changes will be measured in clients' major life areas (physical, economic, social, educational and vocational).

5. The fifth component, and the most critical to later analysis, is the follow-up questionnaire. The questionnaire incorporates status indicators recorded earlier in the client intake and intake supplement forms. Client outcomes will be measured in terms of changes in the clients' key life areas. Measures of client satisfaction are also included in this section.

Progress Report Outline
Centers for Independent Living

Progress reports should cover a three month period and are due fifteen days after the period ends. They should include the following:

Project Title

Beginning and end dates for period being reported

Progress made in following areas:

- A) Impact on Community - List the in-services, public addresses, and presentations given by center staff to agencies and organizations. Include in this section a description of the significant impact (if any) that these presentations had on the community.
- B) Fundraising - Explain the efforts that have been made to secure other than Title VII funds. Include a description of the progress made in developing
 - 1. Fee for service
 - 2. Contracts and grants with other public agencies
 - 3. Contracts and grants with private agencies
 - 4. Private donations
 - 5. Other (specify)
- C) Board of Directors - Describe the board of directors, including the size, mode of selection, member characteristics, percentage of disabled members, and committee structures. Also, describe progress made by the board in the following areas:
 - 1. Development of center's goals and objectives
 - 2. Center budget preparation and review
 - 3. Developing policy in regard to independent living service delivery
 - 4. Establishing community program awareness
 - 5. Developing alternate funding sources
 - 6. Selection and directing Executive Director

If there have not been significant changes in the board since last reporting period, state "no change". Also include in your initial report an organizational chart. If there are any changes from one reporting period to the next which result in changes in the way the center functions, include a new chart.

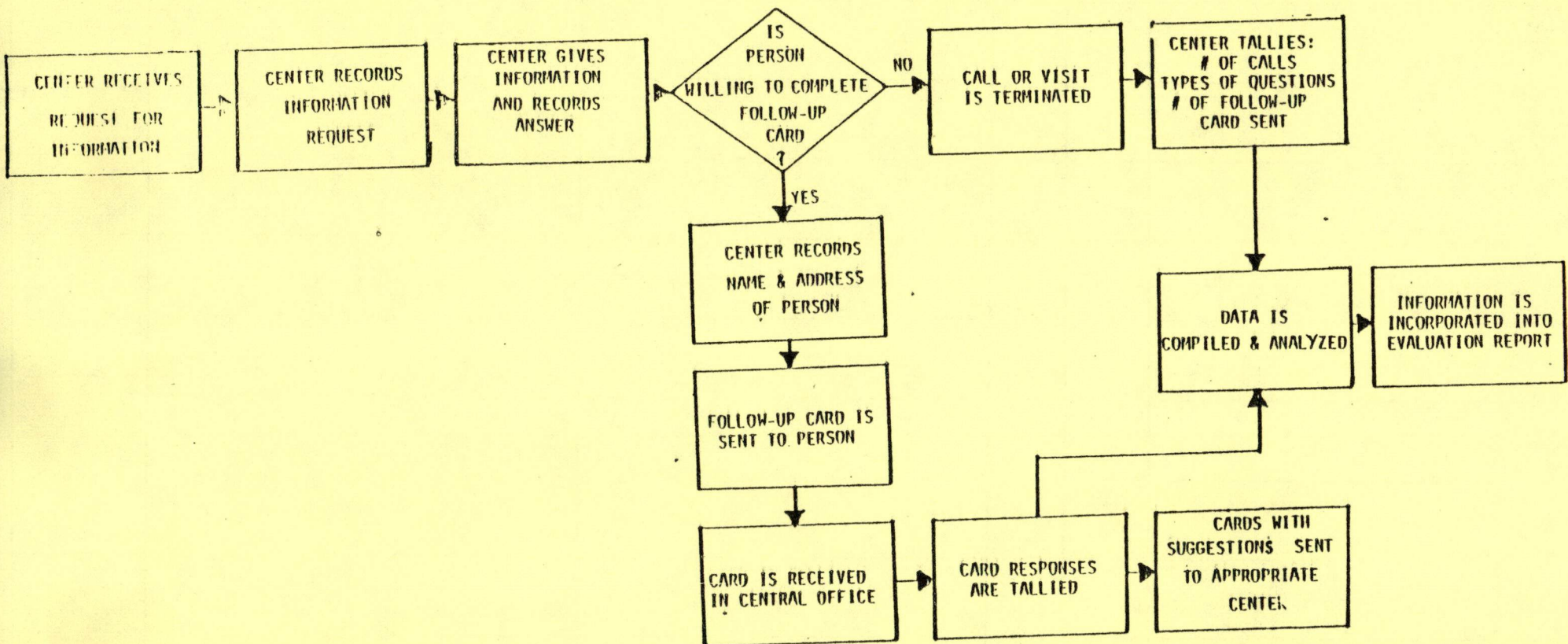
- D) Establishing Service Linkages - Explain the efforts the center has made in developing linkages with local agencies and interagency groups. Include a description of cooperative agreements (either formal or informal) reached and joint ventures (example: workshops) undertaken.
- E) Statistics -
 - 1 - Number of people served this quarter -
This should be a count of the number of different people served during the three month reporting period.
 - 2 - Number of OVR clients served this quarter -
Again, this should be an unduplicated count of people served.

- 3 - Total number of people served during this grant year -
Unduplicated count of people served.
- 4 - Number of self-support plans initiated.
- 5 - Number of service units provided -
A unit of service is defined as one service provided to one person, one time. The following categories are to be used:
 - a) Peer counseling - This is the sharing of experiences by disabled individuals with disabled individuals, and includes counseling done on a one-to-one basis or in a group.
 - b) Housing Assistance - This includes referring individuals to accessible housing, informing consumers about Section 8 and other rent subsidy assistance, and providing other assistance necessary to aid individuals in securing suitable housing.
 - c) Information and Referral - This includes providing information on any topic not listed as a separate category (3a - k). Examples include information on programs and services available in your community. Referral to other "in house" departments should not be included.
 - d) Service Referral - This category includes interpreter, attendant, and reader referrals.
 - e) Advocacy - This includes advising consumers of their legal and economic rights, and assisting them in securing these rights, if requested to do so. Include in this category the number of units of service of
 - 1) individual advocacy - advocating for an individual and
 - 2) systems advocacy - advocating on behalf of a group of people to change the system.
 - f) Special Transportation - If the center has a modified van, count the number of units of transportation provided to consumers.
 - g) Independent Living Skills Counseling and Training - Include ILS training done in a group and on a one-to-one basis.
 - h) Equipment Maintenance, Repair, and Loan - Include in this category classes held to teach consumers how to maintain and/or repair their equipment (wheelchairs, van lifts, etc.), equipment loaned to consumers, repairs done by center staff, as well as referrals made by the center which enables consumers to have their equipment repaired.
 - i) TTY Relay Service
 - j) Architectural Barrier Consultation - This category includes technical assistance the center gives to real estate developers, construction companies, restaurants, stores, and other agencies (both public and private), as well as to consumers and their families.
 - k) Other - (specify)

F) Other

Include in this category any areas you feel need further explanation. If there were changes in center objectives or the center experienced unanticipated problems, please explain in this section.

INFORMATION & REFERRAL
RECORDING PROCESS



[illegible]

COVER LETTER FOR POSTCARD

Dear Friend:

As someone who uses the information services of (name of IL center), you can help us. In order to provide accurate information to others who call, we need to know if the information you received from us was useful to you.

Please take a few minutes to answer the questions on the enclosed card. We would also welcome any comments or suggestions you have. When you have completed the card, please drop it in the mail. No postage is required.

Thank you for your help.

Center name or
name of staff person

INFORMATION AND REFERRAL

FOLLOW UP POST CARD

Did you receive the information you requested?

1. Yes
2. No

Was the information you received useful to you?

1. Yes
2. No

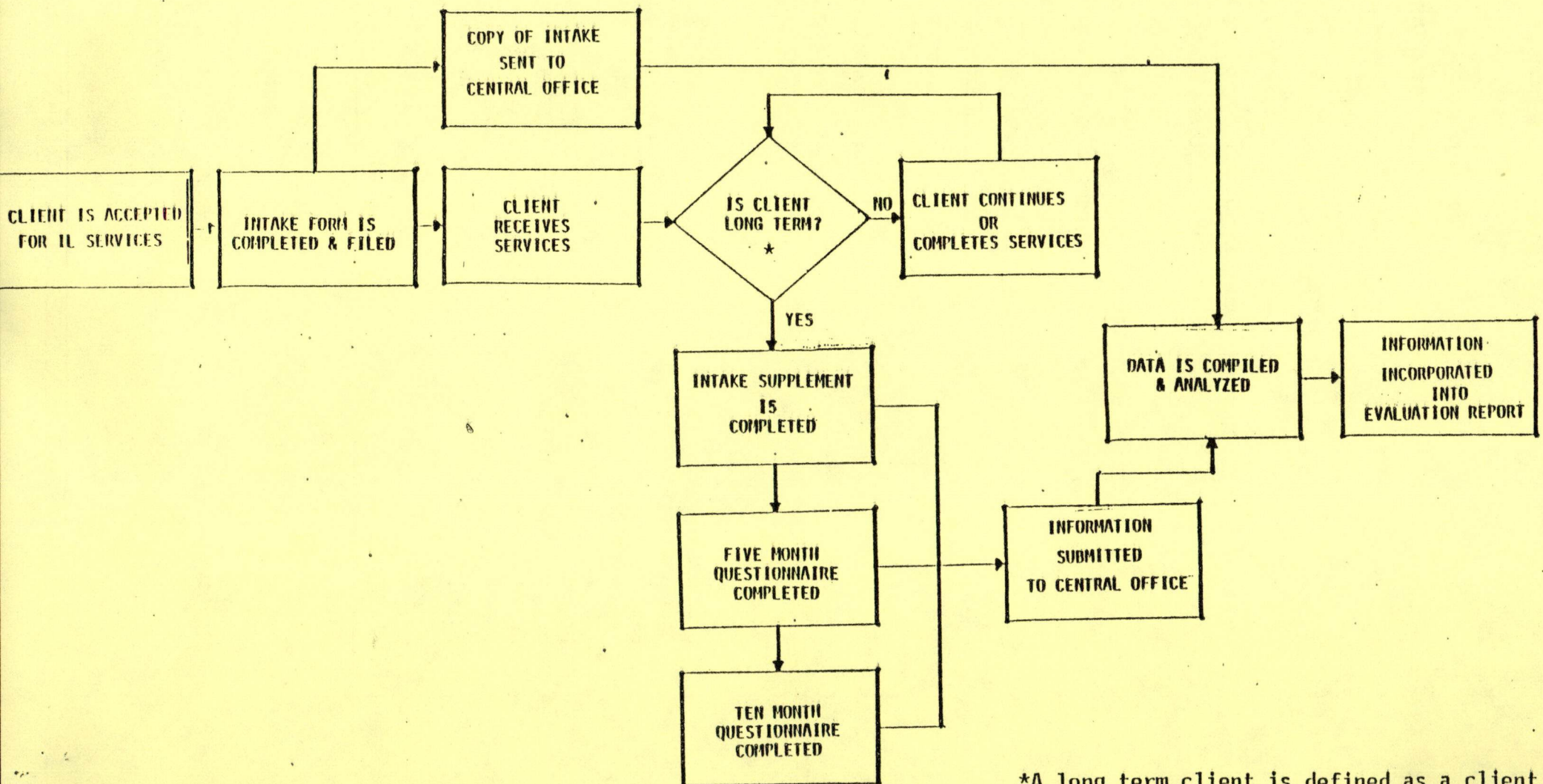
If you were in need of other information would you contact the IL Center?

1. Yes
2. No

Please describe what happened as a result of the information you received.

LONG TERM AND SHORT TERM

CLIENT RECORDING PROCESS



*A long term client is defined as a client who has received 5 or more services from an independent living center

INSTRUCTIONS FOR COMPLETING INTAKE FORM

1. NAME - Persons full name: Last, First, Middle

2. DATE - Date of intake

3. ADDRESS - Including Zip Code

4. TELEPHONE - Including Area Code

5. I.D.# - six digits

Center Codes

Individual

01 - Buffalo (WNYILP)

0001 thru 9999

02 - Rochester (RCIL)

0001 thru 9999

03 - Syracuse (ARISE)

0001 thru 9999

04 - Utica (ARCH)

0001 thru 9999

05 - Albany (CDCI)

0001 thru 9999

10 - Westchester (WCILC)

0001 thru 9999

11 - Manhattan (CIDNY)

0001 thru 9999

12 - Brooklyn (ILH)

0001 thru 9999

13 - Long Island (LICIL)

0001 thru 9999

6. TTY - Does person have one

7. SEX - Circle appropriate item

8. DATE OF BIRTH - Month/day/year

9. MARITAL STATUS - Circle appropriate item

10. AGE - In years only

11. RACE - Circle appropriate item

12. HISPANIC ORIGIN - Circle appropriate item

13. EDUCATION COMPLETED - Circle appropriate item

14. INCOME SOURCES - Circle all appropriate items

List primary source of support.

15. CURRENT EMPLOYMENT STATUS - Circle appropriate item

16. VR STATUS - Circle all appropriate items

17. PRIMARY DISABILITY - Circle appropriate item

Age At Onset Of Primary Disability - if known

18. SECONDARY DISABILITY - Circle appropriate item, if any.

Age At Onset Of Secondary Disability - if known

19. LIVING SITUATION - Circle appropriate item

20. ABILITY TO TRAVEL - Circle appropriate item

21. REFERRAL SOURCE - Circle appropriate item

22. SERVICES REQUESTED - Circle all that apply.

INTAKE

1. NAME: Last, First, Middle Initial

2. DATE:

3. ADDRESS: Street, City, State, Zip Code

4. TELEPHONE:

5. I.D.#:

6. TTY: 1. Yes 2. No

7. SEX: 1. M 2. F

8. DATE OF BIRTH: Month/Day/Year

9. MARITAL STATUS:

10. AGE:

1. Married 2. Widowed 3. Divorced 4. Separated 5. Never Married

11. RACE:

1. White 2. Black 3. American Indian or Alaskan
4. Asian or Pacific Islander 5. Not available

12. HISPANIC ORIGIN:

1. Yes 2. No

13. EDUCATION COMPLETED:

1. Did not attend school 2. Grade School (1-8)
3. Some High School 4. High School Graduate
5. Special Education Program 6. Some College
7. College Graduate 8. Post Graduate Work
9. Other (Specify)

14. INCOME SOURCES: (Circle all that apply)

1. Earnings 2. Family/Friends 3. SSDI 4. SSI
5. Private Inst. 6. Public Inst. 7. Worker's Comp.
8. Veterans Benefits 9. Private Insurance
10. Private Agency 11. Alimony 12. Pension
13. Other (Specify)

Which is primary source of support

15. CURRENT EMPLOYMENT STATUS:

1. Competitive employment, self-employed
2. Competitive employment, wage or salary
3. Sheltered employment
4. Employed, on leave of absence
5. Homemaker
6. Seeking employment
7. Student
8. Volunteer Worker
9. Retired
10. Not employed, not seeking work
11. Other Employment Status (Specify)

16. VR STATUS:

1. Present client
2. Past client

3. Never a client
 4. Unknown
-

17. PRIMARY DISABILITY: (Circle one)

1. Visual
2. Hearing
3. Orthopedic
4. Developmental (MR)

5. Developmental (Other) Specify _____
 6. Psychiatric
 7. Neurological
 8. Other (Specify) _____
-

Age At Onset Of Primary Disability _____

18. SECONDARY DISABILITY:

1. Visual
2. Hearing
3. Orthopedic
4. Developmental (MR)

5. Developmental (Other) Specify _____
 6. Psychiatric
 7. Neurological
 8. Other (Specify) _____
-

Age At Onset Of Secondary Disability _____

19. LIVING SITUATION:

1. Live alone
2. With spouse or friend
3. With dependent children
4. With adult son or daughter
5. With parents

6. With other family
 7. With paid attendant only
 8. Group home
 9. Institution
 10. Other (Specify) _____
-

20. ABILITY TO TRAVEL:

1. Drive own car or van
2. Use regular van service
3. Use bus, taxi or other public transit without assistance
4. Use bus or other public transit with help

5. Get ride regularly with family or friends
 6. Get places only when able to get a ride
 7. Seldom get around because there is no one to depend upon
-

21. REFERRAL SOURCE:

1. Non disabled friend or relative
2. Another disabled person
3. A medical person or health agency
4. At school

5. OVR Office
 6. Another government agency
 7. A newspaper, radio or TV
 8. Other (Specify) _____
-

22. SERVICES REQUESTED:

1. Peer counseling
2. Housing assistance
3. Information and referral
4. Service referral
(Attendant, Interpreter, Reader)
5. Advocacy
6. Special transportation

7. IL skills counseling and training
 8. Equipment maintenance, repair or loan
 9. Architectural barrier counseling
 10. TTY relay
 11. Don't know
 12. Other (Specify) _____
-

INTAKE SUPPLEMENT

Date _____

ID # _____

Please circle, check, or fill in the blanks for the following items, as appropriate.

1. During the last four months about how many times have you seen a medical doctor for routine medical care?

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 more than 15

2. During the last four months how many separate times have you stayed in a hospital or used emergency medical care?

1 2 3 4 5 6 7 more than 7

3. How would you describe your understanding of State and Federal benefit programs related to your disability?

- _____ 1. Complete understanding - I know the ins and outs of benefit programs and can help my friends who are having problems.
_____ 2. Good understanding - I have a fairly good understanding of most benefit programs.
_____ 3. Some understanding - I have some understanding but many parts are still unclear to me.
_____ 4. Little or no understanding - I depend almost entirely on other people for information and assistance.

4. Which of the following answers most closely describes your ability to take care of money matters, (i.e., checking, paying bills, securing loans and making investments)?

- _____ 1. I can take care of all money matters without help
_____ 2. I can take care of all money matters with some help
_____ 3. I can take care of routine money matters
_____ 4. I cannot take care of most money matters at this time

5. Which of the following answers most closely describes your ability to carry out housekeeping work?

- _____ 1. I can do all housekeeping myself
_____ 2. I can do most housekeeping myself with some help
_____ 3. I can do a little housekeeping, with some help
_____ 4. I am largely unable to do any housekeeping

6. Check the following activities in which you have participated during the last three months.

- _____ 1. Work on hobby or craft (like woodworking, knitting, playing the piano)
_____ 2. Participate in a sport or exercise (like bowling, fishing)
_____ 3. Go out for the evening (movies, dinner, nightclub or bar etc.)
_____ 4. Visit with a friend, neighbor or relative
_____ 5. Take a trip (business or vacation)
_____ 6. Shop for groceries, clothing or household merchandise
_____ 7. Obtain household services (shoe repair, cleaners, garden center, etc.)
_____ 8. Other (Specify) _____

7. Did you vote in the last election?

- ☐ 1. Yes
- ☐ 2. No

8. To which of the following kinds of organizations do you now belong?

- ☐ 1. Social/recreational group
- ☐ 2. Organization for disabled people
- ☐ 3. Political action organization
- ☐ 4. Groups concerned with community issues
- ☐ 5. Professional or work-related group
- ☐ 6. Church or religious group
- ☐ 7. Other (Specify) _____
- ☐ 8. None

9. To which of the following organizations do you attend a meeting at least quarterly?

- ☐ 1. Social/recreational group
- ☐ 2. Organization for disabled people
- ☐ 3. Political action organization
- ☐ 4. Groups concerned with community issues
- ☐ 5. Professional or work-related group
- ☐ 6. Church or religious group
- ☐ 7. Other (Specify) _____
- ☐ 8. None

10. In which of the following organizations do you hold an office?

- ☐ 1. Social/recreational group
- ☐ 2. Organization for disabled people
- ☐ 3. Political action organization
- ☐ 4. Groups concerned with community issues
- ☐ 5. Professional or work-related group
- ☐ 6. Church or religious group
- ☐ 7. Other (Specify) _____
- ☐ 8. None

11. What kind of communication services do you receive?

- ☐ 1. Interpreter
- ☐ 2. Reader
- ☐ 3. None

12. What kind of personal assistance do you receive?

- ☐ 1. Nursing services
- ☐ 2. Attendant Care
- ☐ 3. Homemaker services
- ☐ 4. Mobility services
- ☐ 5. Other (Specify) _____

13. From whom do you receive this assistance?

1. Nurse
2. Attendant
3. Homemaker Aide
4. Family
5. Friends
6. Other volunteers
7. None

FOLLOW-UP QUESTIONNAIRE

☐ 5 Month
☐ 10 Month
ID# _____

As someone who uses the services of the (name of center), you can help us. In an effort to assess the effectiveness of the independent living program, we need to know if the services you received from us were useful to you. Please take a few minutes to answer the following questions. Please circle, check, or fill in the blanks for the following items, as appropriate. When you have completed the questionnaire, please drop it in the mail. No postage is required. Thank you for your help.

1. What is your current marital status?

- _____ 1. Married
- _____ 2. Widowed
- _____ 3. Divorced
- _____ 4. Separated
- _____ 5. Never married

2. What are your sources of income now?

- | | | |
|-------------------------|----------------------------|--------------------------|
| _____ 1. Earnings | _____ 5. Private Inst. | _____ 10. Private Agency |
| _____ 2. Family/Friends | _____ 6. Public Inst. | _____ 11. Alimony |
| _____ 3. SSDI | _____ 7. Worker's Comp. | _____ 12. Pension |
| _____ 4. SSI | _____ 8. Veterans Benefits | _____ 13. Other (Spec) |
| | _____ 9. Private Insurance | _____ |

Which is primary source of support

3. What is your status with OVR?

- _____ 1. I am currently an OVR client.
- _____ 2. I have never been an OVR client.
- _____ 3. I was formerly an OVR client.
- _____ 4. Don't know.

4. What is your current employment status?

- | | |
|---|---|
| _____ 1. Competitive employment, self-employed | _____ 7. Student |
| _____ 2. Competitive employment, wage or salary | _____ 8. Volunteer Worker |
| _____ 3. Sheltered employment | _____ 9. Retired |
| _____ 4. Employed, on leave of absence | _____ 10. Not employed, not seeking work |
| _____ 5. Homemaker | _____ 11. Other Employment Status (Specify) _____ |
| _____ 6. Seeking employment | |

5. What is your current living situation?

- | | |
|--|--|
| ☐ 1. Live alone | ☐ 6. With other family |
| ☐ 2. With spouse or friend | ☐ 7. With paid attendant only |
| ☐ 3. With dependent children | ☐ 8. Group home |
| ☐ 4. With adult son or daughter | ☐ 9. Institution |
| ☐ 5. With parents | ☐ 10. Other (Specify) _____ |

6. During the last four months about how many times have you seen a medical doctor for routine medical care?

- 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 more than 15

7. During the last four months, how many separate times have you stayed in a hospital or used emergency medical care?

- 1 2 3 4 5 6 7 more than 7

8. How would you describe your understanding of State and Federal benefit programs related to your disability?

- | |
|---|
| ☐ 1. Complete understanding - I know the ins and outs of benefit programs and can help my friends who are having problems. |
| ☐ 2. Good understanding - I have a fairly good understanding of most benefit programs. |
| ☐ 3. Some understanding - I have some understanding but many parts are still unclear to me. |
| ☐ 4. Little or no understanding - I depend almost entirely on other people for information and assistance. |

9. Which of the following answers most closely describes your ability to take care of money matters, (i.e., checking, paying bills, securing loans and making investments)?

- | |
|---|
| ☐ 1. I can take care of all money matters without help |
| ☐ 2. I can take care of all money matters with some help |
| ☐ 3. I can take care of routine money matters |
| ☐ 4. I cannot take care of most money matters at this time |

10. Which of the following answers most closely describes your ability to travel in the community (the most often used type of transportation)?

- | | |
|--|--|
| ☐ 1. I drive my own car or van | ☐ 5. I get rides regularly with family or friends |
| ☐ 2. I have regular van service | ☐ 6. I get places <u>only</u> when able to get a ride |
| ☐ 3. I use a bus, taxi or other public transit leave without assistance | ☐ 7. I seldom get around because there is no one to depend upon |
| ☐ 4. I use bus or other public transit with someone's help | |

11. Which of the following answers most closely describes your ability to carry out housekeeping work?

- ☐ 1. I can do all housekeeping myself
- ☐ 2. I can do most housekeeping myself with some help
- ☐ 3. I can do a little housekeeping, with some help
- ☐ 4. I am largely unable to do any housekeeping

12. Check the following activities in which you have participated during the last three months.

- ☐ 1. Work on hobby or craft (like woodworking, knitting, playing the piano)
- ☐ 2. Participate in a sport or exercise (like bowling, fishing)
- ☐ 3. Go out for the evening (movies, dinner, nightclub or bar etc.)
- ☐ 4. Visit with a friend, neighbor or relative
- ☐ 5. Take a trip (business or vacation)
- ☐ 6. Shop for groceries, clothing or household merchandise
- ☐ 7. Obtain household services (shoe repair, cleaners, garden center, etc.)
- ☐ 8. Other (Specify) _____

13. Did you vote in the last election?

- ☐ 1. Yes
- ☐ 2. No

14. To which of the following kinds of organizations do you now belong?

- ☐ 1. Social/recreational group
- ☐ 2. Organization for disabled people
- ☐ 3. Political action organization
- ☐ 4. Groups concerned with community issues
- ☐ 5. Professional or work-related group
- ☐ 6. Church or religious group
- ☐ 7. Other (Specify) _____
- ☐ 8. None

15. To which of the following organizations do you attend a meeting at least quarterly?

- ☐ 1. Social/recreational group
- ☐ 2. Organization for disabled people
- ☐ 3. Political action organization
- ☐ 4. Groups concerned with community issues
- ☐ 5. Professional or work-related group
- ☐ 6. Church or religious group
- ☐ 7. Other (Specify) _____
- ☐ 8. None

16. In which of the following organizations do you hold an office?

- ☐ 1. Social/recreational group
- ☐ 2. Organization for disabled people
- ☐ 3. Political action organization
- ☐ 4. Groups concerned with community issues
- ☐ 5. Professional or work-related group
- ☐ 6. Church or religious group
- ☐ 7. Other (Specify) _____
- ☐ 8. None

17. What kind of communication services do you receive?

- ☐ 1. Interpreter
- ☐ 2. Reader
- ☐ 3. None

18. What kind of personal assistance do you receive?

- ☐ 1. Nursing services
- ☐ 2. Attendant Care
- ☐ 3. Homemaker services
- ☐ 4. Mobility services
- ☐ 5. Other (Specify) _____

19. From whom do you receive this assistance?

- ☐ 1. Nurse
- ☐ 2. Attendant
- ☐ 3. Homemaker Aide
- ☐ 4. Family
- ☐ 5. Friends
- ☐ 6. Other volunteers
- ☐ 7. None

20. What services have you received from the Independent Living Center?

- ☐ 1. Peer counseling
- ☐ 2. Housing assistance
- ☐ 3. Information and referral
- ☐ 4. Service referral (attendant, interpreter, or reader)
- ☐ 5. Advocacy
- ☐ 6. Special transportation
- ☐ 7. IL skills counseling and training
- ☐ 8. Equipment maintenance, repair and loan
- ☐ 9. TTY relay service
- ☐ 10. Architectural barrier consultation
- ☐ 11. Other (Specify) _____

21. Did you receive the services you requested from the IL Center?

- ☐ 1. Yes
- ☐ 2. No
- ☐ 3. Can't say

22. How satisfied are you with the services you received from the IL Center?

1 2 3 4 5 6 7

Very satisfied

Very dissatisfied

23. How useful did you find the services you received from the IL Center?

1 2 3 4 5 6 7

Very useful

Not at all useful

24. Would you use the Center again if a need arose?

- ☐ 1. Yes
- ☐ 2. No
- ☐ 3. Can't say

25. Would you refer other people to the IL Center?

- ☐ 1. Yes
- ☐ 2. No

26. Have you referred anyone to the IL Center?

- ☐ 1. Yes
- ☐ 2. No

PENNSYLVANIA
BUREAU OF VOCATIONAL REHABILITATION
Progress Report for CIL Project

CIL Name: _____

Report Period:

From _____ to _____

Contracting Officer: _____

SECTION A (Submit Quarterly)
Progress toward Program Objectives:

Program Objectives
(As stated in your Contract)

Achievement this Quarter

1. Indicate any changes in objectives, schedule for their achievement, and reasons.
Give revised schedule.

2. Explain any differences from work plan

3. State problems encountered, if any, actions taken, and actions planned to remedy problems.

4. Make recommendations (e.g. written policies and procedures, resource gaps collaboration with other resources) which have emerged from your work this quarter. Please provide observations, suggestions, and recommendations (regarding any facet of your program or of the service delivery system in your geographic area) that will promote better services to disabled persons or facilitate your relationship to the Bureau of Vocational Rehabilitation.

Indicate any progress to date in implementing plans for continuing project activities after grant ends.

4. Make recommendations with other staff observations to the service unit. Attached hereto is a list of recommendations.

SECTION C (Submit Quarterly)

Quarterly Client Service Statistical Report:

	Number This Quarter	Number Year to Date
--	------------------------	------------------------

Referrals received

Referrals made to other resources

Client service plans completed

UNITS OF SERVICES DELIVERED:

1. Evaluation

2. Self-Help skills training (ADL)

... group

individual

3. Housing skills training (Assistance/Referral)

... group

individual

4. Homemaking skills training

... group

individual

5. Social/interpersonal skills training

... group

individual

6. Financial

... group

individual

7. Transportation

... group

individual

8. Consumer/Advocacy

... group

individual

9. PCA training/management

... group

individual

10. Personal health care

... group

individual

11. Emergency medical skills

... group

individual

12. Recreational

... group

individual

13. Orientation to Environment/Mobility Training

... group

individual

Advocacy Representation Services

Problem Area	Number of Cases Resolved	Number of Cases Closed	Number of Cases Pending
Health			
Housing			
Financial			
Legal			
Social			
Transportation			

Outcomes of Skill Training

Skill Area	Number Receiving Training This Report Period	Number Completing Training This Report Period	Number Acquiring Skills Year-To-Date
Self-Help			
Housing			
Homemaking			
Social/Interpersonal			
Financial			
Transportation			
Consumer/Advocacy			
PCA Training/Management			
Personal Health Care			
Emergency Medical			

Completed Planned Services

	Number This Report Period	Number Year-To-Date
Moved to Independent Living Setting		
Maintained in Independent Living Setting		
Entered Vocational Rehabilitation Program		
Maintained Employment		

SECTION D (Cont.)

This Report Period	Year to Date
--------------------------	--------------------

NUMBERS OF REFERRALS BY REFERRAL SOURCE

Hospitals - Social Services		
Pennsylvania BVR		
Home Health Agency		
Other Public Agencies		
Private Agencies		
Pennsylvania OVH		
TITLE XX		
Self		
Other		

(Specify)

TOTAL NUMBER OF CLIENTS SERVED BY TITLE VII PROGRAMNUMBERS OF CLIENTS SERVED: By Primary Disability

1. Multiple Sclerosis		
2. Cerebral Palsy		
3. Muscular Dystrophy		
4. Spinal Cord Injury		
5. Spina Bifida		
6. Blind (Visually Handicapped)		
7. Hearing Impairment		
8. Mentally Disabled		
9. Other		

(Specify)

NUMBERS OF CLIENTS SERVED: By Age

17 years of age and under		
18 through 21		
22 through 34		
35 through 44		
45 through 54		
55 through 64		
65 through 74		
75 and over		

NUMBERS OF CLIENTS SERVED: By Sex

Male		
Female		

NUMBERS OF CLIENTS SERVED: By Ethnic Group

White		
Black		
Asian		
Native American		
Hispanic		

This
Report
PeriodYear) 8 NOV 1982
To
DateNUMBERS OF ENTRANTS BY RESIDENTIAL SETTING AT REFERRAL

Hospital
Nursing Home
Transitional Housing
Other Protective Residential Setting
Home
Other _____
(Specify)

TOTAL NUMBER CLIENTS ATTAINING GOALS AND LEAVING PROGRAMNUMBERS OF CLIENTS BY LENGTH OF TIME IN PROGRAM

0 to 3 months
4 to 6 months
7 to 12 months
- greater than 12 months

TOTAL NUMBER OF CLIENTS NOT ATTAINING GOALS AND LEAVING PROGRAM

(Please include a narrative report and analysis
of unsuccessful entrants)

CIL DIRECTOR

(Signature)

Date) 8 NOV 1982

77
77
77
77
77
77
77
77
77
77
77

NUMBERS OF CLIENTS BY LENGTH OF TIME IN PROGRAM

8/11/82
8/11/82

NUMBERS OF CLIENTS BY LENGTH OF TIME IN PROGRAM

White
Black
Other
Native American
Hispanic

D. DRAFT GUIDELINES DEVELOPED BY
RSA CENTRAL OFFICE STAFF

(Sent to Regional Offices for their
review and comment.)

ORGANIZATION

1. What type of organization is the grantee or contractor? If the grantee is a State VR agency, be as brief as possible.
2. Develop a brief history of the program, e.g. was there an independent living program in existence before the Part B grant was made?
3. Obtain grantee and contractor organizational charts and functional statements pertaining to independent living.
4. What is the size of the geographical area served by the Center? What is the potential size of the handicapped population that might be served by the Center?
5. If there is a grantee-contractor relationship, how does it function, i.e. how are problems resolved or issues identified?
6. If there is a grantee-contractor relationship, to what extent does the grantee retain control over Center management?
7. Obtain a current copy of the contract (or written agreement) between the grantee and the Center.

(Interview at least one key representative of the grantee and the contractor to ascertain their observations on the strengths and weaknesses - actual or potential - of the overall organizational structure and how it functions.)

ADMINISTRATION

1. Are delegations of authority written or made orally? There should be a minimum of oral delegation.
2. Are personnel policies clearly stated? Does the Center adhere to them?
3. Does the Center have written personnel policies covering the following: vacation leave; sick leave; working hours; fringe benefits; wage and salary administration; etc.
4. Is there evidence of over-organization or excessive layering of responsibilities, or evidence of under utilization of competent staff, or evidence that certain staff may be assigned too many responsibilities?
5. How are salaries determined?
6. How are salary increases determined and administered?
7. Is there good intra-staff communication through regularly scheduled staff meetings, written office communications, etc.?
8. Have recommendations by the consumer group, grantee, RSA, or others been implemented?
9. What mechanisms have been set up to assure good records control, answering mail and telephone requests, etc.?
10. Is one person designated to assure smooth routine office functioning?
11. How is the Center "manager" kept aware of day-to-day issues and problems?
12. Are leave, pay and time records adequately maintained?
13. Are records of real property maintained and such property identified?
14. Are policy and/or procedure manuals or other system(s) of reference readily available to locate pertinent policies?

(Interview grantee and/or Center staff as determined appropriate.)

CONSUMER INVOLVEMENT

1. Do handicapped consumers have substantial involvement in Center policy and management?
2. Does this involvement emanate from existing or newly constituted Boards, committees, etc.?
3. Has the role of consumers been identified?
4. Is the consumer role advisory or truly policy-decision making?
5. How frequently does the consumer group meet?
6. Are there minutes of consumer group meetings?
7. Is there evidence that consumer directives are carried out?
8. Are matters brought to the consumer group before or after the fact?
9. How are members of the consumer group selected and is there provision for rotating membership?
10. How large is the consumer group and is it representative of the geographic area served by the Center, the severely disabled in general, etc.?
11. Are there sub-committees of the consumer group, and if so, what are they?
12. How is membership in the consumer group determined?
13. Do policy recommendations emanate from the consumer group or are such matters generally brought to the group for consideration?
14. Is the consumer group constituted as described in the application?
15. Is the consumer group involved in Center evaluation, and if so, describe?
16. Is there good communication between/among consumer group members?
17. Is the consumer group actively involved in community advocacy, and if so, give examples?
18. Give a summary assessment of consumer involvement.

(If possible, attend one consumer group meeting and interview three or more consumers to ascertain their role as they perceive it.)

STAFF

1. Describe the number, types and functions of full and part-time staff.
2. Are some staff paid in full or in part from other than the Part B grant, and if so, describe?
3. If the grantee is not administering the Center direct, i.e. a contractor is used, is the grantee furnishing staff assistance, and if so describe? Is such grantee staff paid from the Part B grant? How frequently is grantee staff assistance provided the contractor?
4. Are handicapped persons employed by the Center project? Describe the types of disabilities represented and the types of jobs held.
5. If few handicapped persons are employed by the Center project, is there evidence that such persons were actively recruited, did they apply, were they interviewed, why not hired, etc.?
6. Are handicapped persons working on Center project staff but not paid from Part B grant funds? How are they paid?
7. Is the staffing pattern the same as given in the application? Describe any deviations and why.
8. Have there been problems in recruiting and retaining staff generally?
9. Obtain copies of written job descriptions.
10. Does a staff person function in more than one area, e.g. peer counselor and supervisor, or peer counselor and primary staff person for accessible housing, etc.?
11. Does each staff person know and understand what is expected of him/her, and his/her responsibilities, authorities, etc.?

(Interview all Center staff paid with Part B funds, and as many other Center staff not paid from Part B funds as possible, to ascertain their perception of the purpose of the Center and the population it should serve, and their understanding of their employment functions.)

12. Is the staffing pattern responsive to identified client needs? If not, how are needed services provided? Examples might be volunteers, by purchase of services, training arrangements with a local educational program, etc.
13. Does the Center have staff who are trained in communicating with persons who are deaf? If not, what provisions are made for working with deaf clients?

CASE MANAGEMENT AND SERVICES

1. When were the first services provided? How many (describe) were provided at that time?
2. What services are now provided? Except for I & R services, what services are requested most frequently? Provided?
3. If the Center has an I & R service, describe. If conducted by another agency, e.g. a centralized I & R program for a community, describe how the Center maintains current information in the community I & R service.
4. Are records kept on I & R contacts? Describe, especially requests for unavailable services, actions taken.
5. Describe the initial intake and client assessment process. Does the Center use case management procedures? Describe.
6. How frequently are cases reviewed and plans updated?
7. Are there age, type of disability, or any other eligibility requirements.
8. Obtain sample copies of all case record and related forms.
9. Do the types of services offered agree with those specified in the most current application? If not, why not?
10. How does the Center close, terminate, or suspend case services and for what reasons?
11. Are services provided or arranged that meet identified needs?

(Review case records and interview Center staff.)

CLIENTS SERVED

1. How many clients were served during the first project year or to date?
2. What is the current client daily census of disabled persons receiving continuing services?
3. Is client demographic data available? If yes, obtain same.
4. Are persons with severe multiple handicaps served? Examples.
5. What are the three types of disabilities served most frequently?
6. Does the project serve severely handicapped persons from the following disability groups?

deaf	mentally or emotionally ill
blind	alcoholics
mentally retarded	drug addicts

7. Is there documentation, e.g. case record, of deinstitutionalization and/or prevention of institutionalization of disabled clients? Any anecdotal examples?
8. Are clients being referred to VR? In what numbers? Any examples of successful or potentially successful vocational rehabilitations?
9. Are there examples of the Center assisting successful rehabilitants under Title I to maintain continued employment (in cash or in kind)?
10. What is the age range being served?
11. Are minorities being served? Describe.
12. What is the ratio between males and females being served?

(Interview Center staff and review case records.)

COMMUNICATIONS

1. What public information program(s) are in place to acquaint handicapped consumers, the general public, rehabilitation community, and others interested or active in independent living programs with the Center? What success or resistance has been met? How has the Center attempted to overcome resistance?
2. Does the Center program have an active outreach program, especially such a program directed to minority handicapped groups or groups who because of severe disability may not be aware of the Center program?
3. What channels of communication are open between the Center and consumer groups, groups representing or advocating in behalf of disabled persons?
4. Obtain copies of printed materials and/or lists of materials prepared for the media.
5. Is there a designated person and/or committee responsible for continuing communication efforts, or are such handled mostly on an ad hoc basis?

(Interview appropriate grantee and Center staff.)

Note: Include speaking engagements.

GROUP ADVOCACY

1. Is Center staff, Center consumer advisory group, Center Board, etc., actively involved in local community, regional (state), State or national organized efforts in behalf of severely disabled persons? Are these activities accomplished in a leadership capacity, group member, or both? Examples might be curb cuts, accessible housing and/or transportation, etc.
2. Does the Center have a cooperative relationship with the State's P and A, and CAP programs?
3. Does the Center's staff participate in 504 activities? Describe.
4. Approximately how much Center staff time is devoted to group advocacy activities? Be as specific as possible, using examples where possible.
5. Can positive results be identified that were assisted by the Center program, e.g. increased accessible housing now available as result of staff working with local housing authority?

(Interview Center staff, grantee staff, such other agency staff as may be suggested or identified.)

COOPERATIVE RELATIONSHIPS

1. Does the Center program have formal (written) or informal agreements with cooperating agencies?
2. If formal relationships exist, obtain a copy of the most complete agreement, e.g. that describes the responsibilities and obligations of each agency.
3. If informal relationships are used (there may be a mix of formal and informal), assess how successful they appear to be (give examples), and describe how they function, e.g. joint case staffing or assessments, through consultation, dependent upon individual staff relationships, membership of Center staff on other agency(ies) Boards or committees, etc.
4. Does the Center provide consultation to other agencies?
5. Are referrals made bilaterally?
6. As viewed by Center staff, are interagency relationships productive in behalf of mutually served clients? Any problems?
7. As viewed by other community agency staff, are relationships with the Center program productive in behalf of mutually served clients? Any problems?
8. Does the community served lack specific services that are needed by Center clients? If yes, can the situation be corrected, and if so, how and what steps are being taken to do so?

(Interview Center manager, Center staff making referrals, and two-three staff of cooperating agencies.)

FINANCIAL MANAGEMENT

1. How does the Center maintain control of project funds? The Center should be able to identify excess funds as soon as they occur.
2. Are there written policies regarding the disbursement of funds?
3. What is the procedure for the disbursement of funds from the grantee to the Center? Does a member of the Center staff, other than the fiscal agent, authorize disbursements?
4. Is a member of the Center staff responsible as to the allowability of a proposed expenditure?
5. Is money forwarded to the Center before or after expenditures are made?
6. What type of financial reports are required from the Center? How often are they required?
7. How are financial records maintained by the grantee and the Center and reconciled? How often?
8. Does a representative of the grantee review the accounting records of the Center? If not, how does the grantee assure that proper and adequate records are maintained?
9. Does the grantee require periodic audits of the Center's financial records regarding Part B funds?
10. Who audits the Center's financial records?
11. Review budget requests (e.g. as they appear in the current application), and compare with actual operating costs. Are significant differences justified, explained, etc.? Are reasons given for substantial variations?
12. Does the Center have a fee schedule for specific services? Obtain a copy. Is income generated, and if so, is it accounted for separately and returned to the Government? Used to offset additional Center costs?
13. What is the policy regarding the acceptance of consultation or other fees by Center staff or grantee staff paid from Part B funds?
14. Review the policies concerning consultant services. They should require: (a) a statement of service to be performed, and that it cannot be performed by payment of direct salaries to staff members of the grantee or an affiliated agency; (b) a description of the process of selection of individuals most qualified; and (c) evidence that the fee is appropriate. Is there a written agreement with the consultant showing fee, type of service, performance dates? Is the consultant's service supported by adequate and accurate voucher(s)?
15. Are indirect cost rates, if charged, accurate?
16. Is there assurance that Part B grant/contract funds are accounted for

separately and that there is no co-mingling of these funds and other project income?

17. How is the receipt of goods and/or services documented to support payment for them?

18. Is there a separation of responsibility for the authorization for purchasing and the subsequent payment?

19. Review the timekeeping and payroll procedures. There should be a separation of the various functions.

20. Who on the grantee and Center staff authorizes expenditures for travel? Is there a limit set on the expenditure of funds without prior approval from higher authority, e.g. Board, grantee, etc.?

21. Is there a financial management manual prepared by the grantee or Center?

(Interview financial management staff of the grantee and the Center.)

PURCHASING, CONTRACTING, & EQUIPMENT

1. Is there a written purchasing policy? Does it call for competitive bidding? Under what circumstances is competitive bidding employed, or not employed? There should be documentation showing the bid price and the reason for making the award.
2. If the Center has no policy, what assurance is there that Federal funds are being used for the greatest dollar value?
3. How does the grantee know that the Center's purchasing policies are consistently followed?
4. How are decisions made regarding the selection of the brand of equipment or supplies?
5. Since funds approved for equipment might be lost if not obligated prior to the end of the grant or contract period, is there a requirement that it be purchased early in the funding period?
6. What controls are established for the accountability of equipment by the grantee? By the Center?
7. Does the grantee have equipment inventory records? Is all equipment labeled and periodically inventoried?
8. (same as #7 above but for contractor or Center)
9. Who retains title to the equipment following the end of Federal support?
10. What provision has been made for the maintenance of equipment?
11. How is it proposed to dispose of obsolete, non-functioning equipment? Is there a clear understanding between the grantee and the Center concerning the final disposition of equipment at the close of the project?
12. In what manner does grantee-staff monitor or supervise contracts involving Part B funds?
13. Does work performed by a contractor include an evaluation of his/her performance?

(Interview appropriate grantee and Center staff having responsibilities in the above areas.)

LEGAL RESPONSIBILITIES

1. Is there a written document between the grantee and each Center site regarding overall legal responsibilities for the operation of the Center programs?
2. Does the agreement contain a clause which holds the Center site (or contractor) responsible in the event of an audit disallowance? Are any Center staff with financial responsibilities required to be bonded?
3. Is the grantee named in malpractice and/or liability insurance coverage of the Center program?
4. Do the Articles of Incorporation governing the operation of the Center program have the approbation of an attorney? Obtain a copy of the Articles of Incorporation.
5. What personal liability coverage is available to protect clients, employees, and volunteers who might be injured while engaged in Center activities?
6. Does the Center have the on-going services of an attorney available to it?
7. At minimum, does the agreement (contract) between the grantee and the Center program contain the requirements listed in Part 74, 45 CFR, 74.166?

(Interview grantee and contractor staff having fiscal management responsibilities.)

GENERAL

1. Were unforeseen delays encountered, such as problems in contract negotiation, hiring staff, locating office space, etc., before services could be offered?
2. Is the Center program encountering difficulties now, e.g. key resources such as housing not available or other community agencies uncooperative? If so, what plans does the Center have to overcome these problems?
3. Is maximum use being made of third party payers or similar benefits? If yes, give examples.
4. Is there any evidence that the Center is duplicating existing services? If yes, are there valid reasons for this?
5. Describe the evaluation methods being use, any products thereof, and use being made of such information. Obtain written material if available.
6. Does the Center follow-up with cooperating agencies to ascertain whether a referred client is served? When a referred client is not served by a cooperating agency, what, if any, action does the Center take? Does the Center gather cost data from cooperating agencies when referred clients are served? If yes, how?
7. Does the Center train (direct or by contract) peer counselors, personal care attendants, volunteers? Obtain instructional material if available.
8. Are Center facilities accessible?
9. Is Center setting urban or rural, i.e. which client population does it serve or does it serve both?
10. What activities are being initiated to assure future funding when Federal support ends?
11. How frequently and what types of Center reports are required and by whom, e.g. grantee (or grantee management when project managed direct), Board, consumer group, etc.? Obtain copies.
12. Were there any apparent violations of Section 504 or Title VI of the Civil Rights Act?

(Interview such persons as may be appropriate and/or suggested by either the grantee or Center manager.)
13. Assess how well the Center program appears to be meeting its stated goals and objectives. Are there any slippages? Can they catch up?

E. QUARTERLY COST DATA FORM
RECOMMENDED BY TIMOTHY MUZZIO ET AL IN
INDEPENDENT LIVING REHABILITATION: LESSONS FROM
FIVE DEMONSTRATED PROJECTS

Appendix C

Quarterly Cost Data (Services to Clients)

Client I.D.

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PLEASE DO NOT WRITE HERE

Card 10
1-5

	Description of Services	Expenditures to Date (Beginning From Client Intake)	Percent Project Funds	Percent Other Funds	Other Funding Source 1/
Counseling					
*Adjustment and Personal Counseling		(6-11)	(12-14)	(15-17)	(18-19)
*Vocational Counseling		(20-25)	(26-28)	(29-31)	(32-33)
*Counseling to Family Members		(34-39)	(40-42)	(43-45)	(46-47)
Other		(48-53)	(54-56)	(57-59)	(60-61)
Diagnostic and Evaluation					
*Medical Diagnosis		(62-67)	(68-70)	(71-73)	(74-75)
*Psychological Evaluation		(6-11)	(12-14)	(15-17)	(18-19)
*Intelligence Testing		(20-25)	(26-28)	(29-31)	(32-33)
*Physical Functioning Tests		(34-39)	(40-42)	(43-45)	(46-47)
Work Evaluation/Work Adjustment		(48-53)	(54-56)	(57-59)	(60-61)
Other		(62-67)	(68-70)	(71-73)	(74-75)
Physical and Mental Restoration					
Surgery and Treatment		(6-11)	(12-14)	(15-17)	(18-19)
*Occupational/Physical Therapy		(20-25)	(26-28)	(29-31)	(32-33)
Prosthetic and Orthotic Devices		(34-39)	(40-42)	(43-45)	(46-47)
Hospital and Convalescent Care		(48-53)	(54-56)	(57-59)	(60-61)
*Medicine or Drugs		(62-67)	(68-70)	(71-73)	(74-75)

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Card 11
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Qtr. * Yr. **

*Codes for Quarters:

1 - 1st quarter (January 1 - March 31)
2 - 2nd quarter (April 1 - June 30)

3 - 3rd quarter (July 1 - September 30)
4 - 4th quarter (October 1 - December 31)

**Use last 2 digits of year.

76-78
79-80-12

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-2-

	Description of Services	Expenditures to Date (Beginning From Client Intake)	Percent Project Funds	Percent Other Funds	Other Funding Source <u>1/</u>
Other Restoration		(6-11)	(12-14)	(15-17)	(18-19)
Training					
*Personal Adjustment Training		(20-25)	(26-28)	(29-31)	(32-33)
*Vocational Adjustment		(34-39)	(40-42)	(43-45)	(46-47)
College or University		(48-53)	(54-56)	(57-59)	(60-61)
Business School or College		(62-67)	(68-70)	(71-73)	(74-75)
Elementary or High School		(6-11)	(12-14)	(15-17)	(18-19)
Vocational School		(20-25)	(26-28)	(29-31)	(32-33)
On-the-Job Training		(34-39)	(40-42)	(43-45)	(46-47)
Other		(48-53)	(54-56)	(57-59)	(60-61)
Placement		(62-67)	(68-70)	(71-73)	(74-75)
Maintenance					
Basic		(6-11)	(12-14)	(15-17)	(18-19)
Supplemental		(20-25)	(26-28)	(29-31)	(32-33)
Services to Family Members		(34-39)	(40-42)	(43-45)	(46-47)
Transportation		(48-53)	(54-56)	(57-59)	(60-61)
Aid and Attendant Services		(62-67)	(68-70)	(71-73)	(74-75)

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Form Administered*

*Codes for form administered:

- | | |
|-------------------|-------------------|
| 1 - New | 4 - 3rd follow-up |
| 2 - 1st follow-up | 5 - 4th follow-up |
| 3 - 2nd follow-up | 6 - 5th follow-up |

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Description of Services	Expenditures to Date (Beginning From Client Intake	Percent Project Funds	Percent Other Funds	Other Funding Source 1/
Other				
Phone and Environmental Modifications	(6-11)	(12-14)	(15-17)	(18-19)
*Coordination of Services	(20-25)	(26-28)	(29-31)	(32-33)
*Other Equipment	(34-39)	(40-42)	(43-45)	(46-47)
*Miscellaneous	(48-53)	(54-56)	(57-59)	(60-61)

*Indicates categories not currently included in program regulations guides for reporting VR costs

1/ Codes for Other Funding Sources

- 01 SSI
- 02 SSDI
- 03 AFDC
- 04 General Assistance (State Programs)
- 05 VA
- 06 Medicaid
- 07 Medicare
- 08 Title XX
- 09 Workmen's Compensation
- 10 BFOG
- 11 Private Foundations or Associations (specify, e.g., H.D.A., Easter Seals, etc.)
- 12 Other VR Funds (I & E, Extended Evaluation, Regular Program)
- 13 Family
- 14 Self
- 15 Other (Specify)
- 99 Don't Know

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