

REAUTHORIZATION OF THE REHABILITATION ACT

DIRECTIONS

from

A National Leadership Summit Meeting

Hosted by

University of Southern California

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IN FRIENDSHIP AND RESOLVE

The Meeting Steering Committee gratefully acknowledges the superb preparation and contributions of all the participants who attended this historic national leadership gathering.

This event demonstrates the convergence of interests and the remarkably unified vision among the breadth of individuals, organizations, associations, agencies and corporations who shared in its work.

In order for America to bring about the long overdue paradigm shift called for in these proceedings, a pyramid of involvement is urgently needed. We must firmly press for the complete reconstruction and rewriting of the entire Act.

This document attempts to set the strategic angle of change. It is not complete. The financial impact will be significant and must be calculated. It does not yet have the data base required to compel Congress to share in this vision. Considerable detail in relationship to specific Titles of the Act is left to your expertise to develop consistent with the principles and the scope set forth here.

Clearly, to fully realize a national, just, and economical system for services, Congress and America must also establish:

- * A coherent, sufficient income policy for all Americans;
- * Universal access and coverage to health care; and
- * Safe, affordable, accessible, and adequate housing.

Nevertheless, profound change must start somewhere; and from our experience with the Americans with Disabilities Act, we are in the breach!

Therefore, we call upon you, the reader, to bring your power, imagination, resources, personal and professional network to bear to make these directions the next reality in federal statute.

Take these **ACTIONS** for the Reauthorization:

1. Share and debate the ideas contained in this report. Do not accept minor modifications, tinkering or incrementalism. Strive for the paradigm shift. Use your finite energy to bring about the major breakthrough.

2. Obtain endorsements and resolutions from every possible public and private source.
3. Communicate these endorsements to your Congressional offices and the appropriate committees.
4. Insist on whatever depth and extent of Congressional study and hearings are needed to ensure this strategic agenda is enacted.
5. Form or join a reliable coalition within your state to bring about the changes needed.
6. Build or join phone and fax communication networks to stay up to date with actions in Congress.

If, as with the Americans with Disabilities Act, we again marshal the will, demonstrate the broad base of public concern and support, and focus on what is common to us all, we will contribute mightily toward furthering the American Dream.

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TABLE OF CONTENTS

| | Page |
|------------------------------------|------|
| IN FRIENDSHIP AND RESOLVE | ___1 |
| OPENING REMARKS BY: | |
| • Justin Dart___ | 4 |
| • Sandra Parrino | 6 |
| SHARED DIRECTIONS | |
| THE FIVE BREAKTHROUGH CONCEPTS. | 8 |
| ENTITLEMENTS & ELIGIBILITIES. | .10 |
| VALUES . | .11 |
| SUNSET . | .12 |
| SPECIFIC DIRECTIONS: | |
| • Administration. | .13 |
| • Careers_____ | .14 |
| Youth Services. | .15 |
| • Independent Living. | .16 |
| • Program and Interagency Systems. | .18 |
| • Technology._____ | .20 |
| • Personnel_____ | .21 |
| APPENDIX | |
| PATRONS. | 23 |
| LIST OF PARTICIPANTS | .24 |

OPENING REMARKS BY JUSTIN DART*

I congratulate U.S.C., Ralph Bledsoe, Bill Bronst-on, Lex Frieden, Colleen Wieck, and the other organizers of this conference to address an essential task—refining and expanding the Rehabilitation Act to serve all. And I congratulate you on assembling a group of truly distinguished authorities.

Thanks to a great President and a great Congress, thanks to the great patriots in this room, ADA is law.

ADA is a landmark in the evolution of the human self-image—the world's first declaration of equality for people with disabilities by any nation. But most important, ADA is a promise to be kept

Two years of debate in Congress, 3,000 people on the White House lawn finally captured the attention of the world for our cause.

America is watching. The World is watching. We have a once in a millennium opportunity to make a fundamental improvement in human culture. But if the promise of ADA is not kept in the everyday lives of Americans with disabilities, if ADA is noted principally for neglect, noncompliance and bickering, the cause of empowerment will be set back for generations everywhere.

Christmas day I went to Arlington National Cemetery to consider my responsibility. I looked out over the little stone symbols of lives given so that we could advocate for ADA. I thought of the hundreds of millions in future generations whose destinies will be profoundly affected by what we do now. I thought of the people with disabilities laying in the streets of New York and Bombay, of the people isolated in the shacks of Pine Ridge and the back rooms of Beijing and Lagos. And I knew that I was not doing enough.

Most initially successful revolutions do not keep their promises. They are frustrated at the moment of victory by apathy and disunity.

Many of us are tired after long years of struggle. It is tempting to relax and enjoy the aura of political triumph—the positions, the recognitions, the prestige.

I am tired. And to tell you that I am never tempted to compromise principle for prestige would be dishonest and arrogant.

But I—we —"have miles to go and promises to keep before we sleep."

We must maintain and greatly expand the united action which carried us to victory for ADA.

We must once again overcome the obsessions with turf, pork barrel politics, and personal power. position and pride that have defeated the human dream so often in the past.

We of the disability community must unite as never before. We must celebrate and spread the message of ADA in every community. We must join together with business, government, operators of public facilities, and service providers to implement ADA in every community. Because ADA is the essential philosophical, attitudinal, and legal foundation for everything we want to do at this meeting.

And to keep the promise of ADA in real life we must create, enact and implement an expanded, comprehensive Rehabilitation Act

Our first priority is to develop an already good, but incomplete Rehabilitation Act into a comprehensive process through which all people with disabilities will empower themselves to participate fully in the mainstream of the culture.

The process must enable people to take conscious control of and responsibility for their own lives.

The process must motivate and empower people to fulfill their potential for productivity in terms of those things which constitute quality of life for self and society. Life quality productivity is the substance of equality, of independence, of prosperity, of psychological and social security, and of happiness.

Families, schools, commerce, government, public media must be fully involved in the rehabilitation process.

An effective rehabilitation system must provide for lifelong single point of entry counseling, information, and referral tied together by a computer network connecting all clients, all public and private services, all information sources, and all authorities on the local, state, and national levels. Congress could provide seed money for such a computer network. It would be the beginning of a positive revolution in a now fragmented service and information system.

Cost? There is no better way to increase the quality and strength of family, local, state, and federal economies, and to reduce budget deficits, than to invest in the employment and other life quality productivity of all people with disabilities.

One final advice. Aim high. Be comprehensive. Create a process which will be a complete component of a truly responsible society in the 21st century. Do not be intimidated by fears that optimal solutions are politically and economically impossible.

The pioneers of ADA and every other great advance for human kind have been greeted with cries of "impossible." Our great nation already has the human, material, technological, and methodological resources to create a life quality society that exceeds the imagination of Utopian fiction. Success simply requires positive, unifying, courageous leadership to reallocate resources from obsolete status quo practices to life quality productivity.

The key to success is unity. Working together we can transcend self-defeating perceptions and practices and create a Rehabilitation Act that will combine the best of the present and the possible, and truly empower.

We must unite. Together we have overcome. Together we can and we shall overcome.

OPENING REMARKS BY SANDRA PARRINO

Good Morning, its a pleasure to be here. The National Council is an independent federal agency originally created by Congress in 1978 as an affiliate of the Department of Education and was granted independent agency status in 1984. Its members are appointed by the President, with the advice and consent of the Senate.

By law, the National Council is charged with "promoting the full integration, independence, and productivity of individuals with disabilities in the community, schools, the work place, and all other aspects of American life." Our duties include providing advice and guidance to the heads of federal agencies with disability responsibilities and recommending to the President and Congress legislative proposals and other initiatives.

As most of you know, ADA was originally proposed by the National Council. If the ADA was the legislation that opened the door of opportunity for persons with disabilities, then the Rehabilitation Act is me legislation mat must prepare persons with disabilities to proceed through that door. Over the last four months, the Council has received input regarding the reauthorization of the Rehab Act through two sets of hearings based on testimony of experts, consumers with disabilities and rehab professionals who recommended many, many changes in theAct

In terms of the overall act, I heard one reoccurring, but not surprising, theme. The rehabilitation process, as currently practiced by the Federal/State vocational rehabilitation partnership is slow, bureaucratic and inefficient. Some of the regulations and amendments in the Act are a hybrid of old and new and they have not been put together on a comprehensive set of logical tides and regulations which truly enhance and encourage people with disabilities to reach their utmost level of integration and productivity. The cornerstone of the Act is a vocational rehabilitation program which began shortly after World War I. There are many traditions in the Act that are felt to be obsolete and should possibly be abandoned. People spoke to the Council about the importance of taking time not just to reauthorize the Act, but possibly to reconstruct it!

The following are some of the many excellent questions the Council heard during the hearings, which would need to be addressed when such a reconstruction occurs:

- Why, according to census data, has the percentage of people with disabilities in the labor force declined since 1981?
- What kind of accountability system and quality assurance process could be developed which focuses on quality in outcomes?
- If some States have consistently poor outcomes for people with disabilities, how should they be dealt with?
- How can work disincentives which are contained in the rehab process itself, as well as in other programs such as Social Security, be simplified and streamlined? with
- Should the Act be amended to prohibit the applications of economic needs standards in connection any vocational rehab service provided for an individualized written rehab program?
- Is the Rehab system appropriately and adequately serving people with long-term, serious mental illnesses and severe physical disabilities? Major emphasis continues to be on quantity of services.

Counsellors feel tremendous pressure to "close" as many clients as they can each year. Ultimately, their job performance is largely measured according to numbers of "cases closed" (people rehabilitated), not the quality of services provided individual clients. This translates into a hesitancy on the part of counsellors to accept individuals who may be "risky". That is, where the prospects of eventual success are unclear. People with serious mental illnesses or severe disability are particularly hurt by this practice.

- How can the Act encourage innovative program options for emerging groups of people with disabilities such as those with AIDS, traumatic brain injuries, people with severe mental illnesses and environmental disabilities?
- How can control of the rehab process become a reality for people with disabilities? The rehab process has remained substantially controlled by the rehab counsellor. Many feel that the locus of control of the process should be shifted from the counselor to the consumer (the guardian or the person with a disability seeking services.) The entire Act should be restructured and modernized to adopt more of the principles of consumer involvement and consumer control.
- How to provide people with disabilities with the opportunity to make clear choices as to those services they wish to access in order to each me goal, which is employment?
- Would a voucher system be feasible?
- How can funds available through this Act be used to the greatest extent possible for direct services that lead to employment?
- How can the Act become a primary vehicle for preparing individuals with disabilities for lifetime careers? Job placements often are not consistent with today's job market, which clearly leaves people with disabilities out of competition for future opportunities because of the emphasis on entry level positions instead of careers. Emphasis on entry level positions is a disincentive for some people with severe disabilities. Preparing for a lifetime career would shift the focus of the Act from delivery of conventional rehab services, leading to low level outcomes, toward continuing support that develops careers for people.
- How can the Act be strengthened to insure that the placement of individuals into competitive employment in the most integrated setting is always the top priority?
- How can the Act be changed to ensure the life long supports and services are available for people with severe disabilities to remain in the work force? (as contrasted with the current time limited concepts.)
- How should personal assistance services to individuals with disabilities be included in the Act? Personal assistance services would include any supportive service from an individual to a person with a disability who needed such a supportive service in order to live independently and to work in the community.
- How can the language appearing in Title VII, Part B requiring consumer involvement characterize the Act as a whole: people with disabilities should have a leadership role in and be employed by all programs authorized by the Act.

I hope these provide a lead to what is most pressing, most challenging for Americans. Representatives from the the Board and staff of the Council will share our recommendations with you over these next three days.

In closing, I would like to salute the conferees of this summit as well as all of you who are here as leaders committed to the enhancement of and quality of opportunity for people with disabilities. Just as we all worked together on the passage of ADA, The National Council on Disability would like to continue to work jointly with you so that we may support progressive reform of the Rehabilitation Act. Thank You.

FIVE SHARED BREAKTHROUGH CONCEPTS

1. A NEW NAME

There shall be a *new name* for the "Rehabilitation Act" in order to properly represent the full scope and expanded purpose herein. Suggestions included:

- Americans with Disabilities Act II;
- Americans with Disabilities Implementation Act;
- Americans with Disabilities Community and Career Act;
- Services for Individuals with Disabilities Act;
- Independent Living Act;
- Disability Storm

2. CAREERS:

The concept of *personal careers* must replace the current terminology and practice of vocational placement, entry level jobs, and "closure."

- A career creates the most significant identity and source of esteem for a person in our society.
- A career implies a lifelong process of personal futures planning that is based on the individual's choice to participate.
- A personal futures plan is based on self-determination principles and self-satisfaction. It builds upon the person's strengths and capacities. It is oriented to a personal vision of the future. It draws upon family, friends, and informal support networks to provide ongoing support to become a reality.
- Career choice is based on informed decision making and work experiences.
- Careers are coordinated with the person's education and continuing education.
- A career allows for job changes, flexibility, success, and failure, with no minimum or maximum hours of work.
- A career builds income over time and requires financial planning, economic security, and benefits including access to health care.
- A career encourages enriched, changing, and expanding relationships with employers, co-workers, families, neighbors, and friends.
- A career provides access to quality technology to improve learning, performance, communication, independence, and interdependence.
- A career provides opportunities to use generic services and fosters natural relationships.

The Act should direct resources only to integrated career options and systematically redirect existing funds toward careers that are integrated.

3. COMMUNITY ACTION

A *Community Action Title* must be added to the Act to implement an innovative advocacy model which assists the individuals with a disability to:

- Know and obtain service and resource options available to all people in the community and assist generic services to be fully accessible to all people.
- Make choices about what supports exist or need to be created to successfully experience full integration in community life and to achieve a satisfying and productive career pathway.
- The state agency, directly with independent living centers, will develop and implement a comprehensive community organizing capacity, staff competency, new networks, and formal agency interrelationships within each locale to advance full access, acceptance, and esteem afforded all persons with disabilities.

4. YOUTH

Youth (ages 3 through secondary education) with disabilities shall be fully included in the service and benefits of this Act and shall be provided life and career planning as a specific service of the state agency to be formally coordinated with the state education agency and P i . 94-142.

Funding shall ensure fully integrated programming among youth with and without disabilities through personal and group advocacy, service coordination, and a community action paradigm linking public and private sector resources.

Coordination with and equal access to all existing youth services (social, health, education, vocation, etc.) shall be provided based on personal strengths and capacities rather than the diagnostic label and the deficit based current model.

5. SUSTAINABLE TECHNOLOGY

An *entitlement to technology and related supports* is essential lifelong. The provision of this entitlement must be referenced to the individual's personal futures plan, fostering uninterrupted ability to work and thrive in the community. Further, such benefit must be based on regular and periodic assessments to ensure that an optimal match exists between support services, technology, and the present and changing needs and development of the individual to sustain a career and independent living.

Acquisition, maintenance, appropriate on-hand duplication, warranties, and replacement costs must be guaranteed to ensure reliability, utility, and uninterrupted use of technology.

A new stream of funding within this Act must be established to this end when Title XIX and related medical model reimbursement programs and subsidies do not currently cover such costs.

ENTITLEMENT

What services and benefits are required?

1. The purpose of the Act shall be to achieve: •integrated, independent community living, •careers, -lifelong contribution or employment through the promotion of a comprehensive, coordinated, and sustainable array of services and resources which empowers the individual and emphasizes self-determination.
2. Scope of services shall be defined as any good or service required to achieve and maintain integrated, independent community living; career related employment; and related activities defined by the individual through a personal futures plan.
3. Entitlement provisions must be established which clearly specify that once edibility conditions are met an individual is entitled to the full range of services and resources, with no means test, as needed throughout one's lifetime.
4. Establish technology and technology services as a sustainable, primary and singular service. These shall be considered rightful tools to access under ADA and 504 intent
5. Develop new strategies to define and detect people who abuse the system for economic gain that are not more costly or dehumanizing than the abuse itself. (Minority opinion)

ELIGIBILITY

Who shall receive benefits and services?

A range of eligibility specifications are offered:

- a. Establish a universal disability criterion. Create a mandatory, uniform eligibility/disability determination for all recipients of federal financial assistance.
- b. Establish presumptive eligibility for all people with disabilities as defined by ADA and 504. Priority is given to persons with severe disabilities to ensure their access to service with definition of severity based on functional criteria.
- c. Accept all other established definitions of disability including SSA, DD services, special education, and ADA. Eliminate duplication of other disability determinations without regard to previous work, past services, or severity of disability. Eliminate duplication of testing.
- d. The individual self detenninca ciigiuiiniy. The Act must recognize that assessments must focus on the interaction between the individual and the communiy environment.

Eligibility must **be lifelong in duration.**

VALUES

Congress must enact a *Preamble* which articulates the breakthrough values and philosophy of integrated independent living and careers. This Preamble should reflect the principles of the Americans with Disabilities Act and reinforce the national commitment to the full civil rights of all people with disabilities. The Preamble sets the direction for all programs and services that promote the social and economic independence of people with disabilities.

The Preamble shall also accentuate a new emphasis on specific youth needs and services in the Act regardless of class, race, gender, and geographic diversity.

At the individual level, the critical values are:

- Personal Empowerment: characterized by choices and information, individual control, and self-determination; access to economic security, accountability, ambition, and expectation.
- Access to individualized services that are coordinated, comprehensive, adaptable, and responsive.
- Outcomes defined by level of independence, productivity, and full social integration.
- Accountability based on quality of life, economic goals, consumer satisfaction, and personal responsibility.

At a generic level, citizens are entitled to:

A career (broadly defined).
Social and family life.
Civil responsibilities, privileges, and rights.
Informal choices and valued outcomes.
Integration into community life.
Equitable financial incentives.
Quality health care.

At a system level, the system that supports these values in the spirit of the ADA must:

Be individually controlled, driven, and directed.
Be fundamentally equally accessible.
Support inclusion and integration.
Support the individual and family.
Be committed to empowerment
Assist persons with the most severe disabilities first.
Use outcome measures rather than process measures.
Respect individual's privacy and confidentiality.
Support social change and advocacy.
Do away with the deficit based medical model.
Provide technical support, education, and training to all covered by the Act
Holistically address life issues.
Acknowledge technology as an equalizer to address person-environment match, not fixing individual deficits.
Guarantee full access to technology.

SUNSET

In contradiction to this system of values and program design, the hallmarks of traditional vocational rehabilitation stand in sharp distinction.

Therefore statute language, regulations, procedures and practices underpinning:

- **Case closures.**
- **The determination of feasibility and the exclusionary orientation therein.**
- **The traditional deficit based medical model**

all of which are inimical to this Act must be explicitly rejected and replaced.

ADMINISTRATION

1. **Governance** — The Act will define:
 - a. A mandated independent agency at the state level with a full time director.
 - b. The agency is responsible to a governing board of (15-20) citizens appointed by the Governor and approved by the Legislature. The majority of the board will be direct consumers. The Board will also include parents, chairs of ILCs and employers. The terms of members will be staggered.
 - c. Strengthen mandated interagency coordination at the state and local level.
 - d. The governing board has the power to approve the State Plan.
 - e. Local control needs to be built into the Act. This process and structure of how to implement local control is left to the states.
2. **Location**—Place in HHS (2 votes), place in Labor, place in "National Disabilities Administration" (consolidate RSA, OSEP, DD, NIDRR, PCEPD) with a council over this Administration, place in a new independent agency —RSA (5 votes).
3. **Local control**—Local community participation is critical and must be written into the Act Planning must be community up, improve communication, and pull various disability groups together.
4. **Private Funds** — Require states to fully match, allow use of private funds with no penalty for overmatching.
5. **Voucher** — The Act should allow a pilot of vouchers in several states to determine best practices.
 - a. Empower the individual so that he/she can receive the services wanted and have final approval of the IWRP.
 - b. When eligibility is obvious, persons should be automatically assigned.
 - c. This financial voucher system would enable individuals to choose support services which were responsive and satisfactory.
 - d. The individual would have final decision-making regarding services, evaluation, or equipment with:
 - Dollars linked with IWRP.
 - Dollars follow through the IWRP to the individual then to services.
6. **Appeals** - Eliminate the final authority of the VR Director over the hearing officer. Require mediation or arbitration to resolve disputes. Participants shall have a choice of hearing officers.
7. **Program Evaluation**—Program evaluations and rewards derived from them must be broadened to include qualitative (process) criteria, long-term support, consumer satisfaction, and other measures beyond case closure and entry level placement. Develop weighted standards and eliminate status measures.
8. **State Plan** - State plan should have stringent requirements in order to promote uniformity in the provision of services in the state.

CAREERS

1. Impact of the Careers Concept:

- a. Entitlement establishes a lifelong commitment ID services contradicted by closure.
- b. Services should be provided in integrated settings. Finances can only be used to promote integrated work options.
- c. Systematic application of personal futures planning.
- d. Recognize the limited access to current services (unemployment, underemployment, waiting lists).

2. Definition of Services—Define support, assistance, and services broadly to mean whatever it takes to accomplish meaningful goals. Eligible services should:

- a. Be defined by an individualized personal futures plan.
- b. Invest in enabling the community and generic services to meet the individual's specific needs.
- c. Include but not be limited to: attendant care, assistive technology, personal support, transportation assistance or support, training, co-worker support, counseling.
- d. Be accessible lifelong in response to need.

3. Job Placement—a) eliminate "closure" as a success measure and substitute record of successful intervention, b) informed decision making/self-determination, c) part of a negotiated and individualized support and training plan (including technology).

4. Community Awareness—Fund and develop a media campaign with career focus, for youth, communities and employers (separately). Participate in advocacy campaigns for social and physical accessibility.

5. Technology—a) Provide information and build awareness; b) use formal decision-making process for individual choice; c) develop comprehensive technology plan for accessing resources, purchasing instruction, maintenance; d) secure on-going discretionary resources; e) operational data bases which contain user friendly information on devices, access to used equipment; f) increase public exposure to the potential of technology.

6. System and Coordination—Mix and match funding from health, DD, SB A, State Department of Employment, HUD, SSA, Education (P.L. 94-142), transportation.

7. Data Base - Establish and maintain data on employment, income and benefits, trends and demographics, satisfaction surveys and school databases.

8. Private Sector Matching & Assistance—Fund raising for services, career development, and organizing work must be the department's responsibility.

YOUTH SERVICES

1. Service must be available to persons based on a range of need and/or desired outcome rather than age limits:
 - a. Availability of services should be assured from age of onset of disability.
 - b. Special attention must be paid to youth and those at risk of "falling between the cracks" for service eligibility, access and availability.
 - c. Review all aspects of the Act to ensure that people living long lives (over 65) are not excluded by recommended policies.
2. Provide for staff and fiscal support for integrated youth programming (e.g., California's Project Interdependence and other youth self-determination projects.)
3. Independent Living Programs should be established in all county and selected local school-based settings (*Student Self-Determination Centers*) which, in content and process, develop the skills and attitudes vital to maximizing/optimizing personal independence (e.g., self-esteem, empowerment, assertiveness, self-determination, advocacy, peer support control) by all students with disabilities.
4. Mandate state grant allocations to provide career and transitional counseling for youth.
5. Determine and promote a range of incentives designed to encourage the participation of the private sector (companies and/or individuals) in the career development and retraining of individuals with disabilities.
6. Mandate and establish mechanisms of individual service coordination which link private and public resources to insure the purchase of services, programs and technology. Mandate the creation of Individual Service Coordinator trained and authorized to work in partnership with the individual and family members to coordinate and monitor the delivery of interagency services.
7. The Act must be integrated with P.L. 94-142 and assure that mandates are implemented in practice. Undertake ongoing side by side law reviews other Federal legislation affect people with disabilities to ensure full coordination and mutual reinforcement of values expressed above.
8. Mandate that support services for family and/or advocates be provided as needed to increase the likelihood of success for individuals with disabilities in their development.
9. Continue to promote and model the appropriate portrayals of people with disabilities in all forms of media.
10. Coordinate and endorse all efforts toward prevention and amelioration of disabilities due to life style, accidents, and environmental factors.
11. Mandate a change in the National Census to include all people with disabilities and implement a nationwide survey to accurately assess the scope and functional significance of disability in America.

INDEPENDENT LIVING

1. The New Act will be reorganized as follows:
 - a. Title I, Civil and Legal Rights Protections:
 - 1) Includes all provisions of Title V.
 - 2) Includes legal protections. Redesign system to include PL. 94-142 legal right concepts in Client Assistance Program Services and Protection & Advocacy Legal Services Model.
 - 3) Include specific language on mandated systems and policy integration at the federal level.
 - 4) Include oversight of technology and communication in the mandate of the access board.
 - 5) Move Title IV (National Council on Disability) to Title I.
 - 6) Include advocacy based on I & R.
 - 7) Move Title VII A to Title I.
 - b. Title II, Comprehensive Services (career and community access services):
 - 1) Facilitate individual movement through system through strengthened identification, outreach and information.
 - 2) Require a newly constructed state council to develop, oversee, and evaluate the state plan and its implementation:
 - a) Act should specify criteria for plan.
 - b) Support and training shall be provided to carry out program for the Council.
 - c) Funding should be available to support Council work.
 - d) The Council should be appointed by the Governor.
 - e) The Council should represent all disabilities and be composed of a controlling number of persons with disabilities.
 - f) The Council should recommend and review the choices for Director of the designated state agency to the governor where appropriate.
 3. Services under Title II should be:
 - a) Lifelong in duration.
 - b) An entitlement to eligible participants.
 - c) Integrated, using a team approach.
 - c. Title III, Independent Living Centers:
 - 1) National Council on Disability standards should be written into law.
 - 2) Direct funding to Independent Living Council (remove state's right to preempt or withhold funds).
 - 3) Mandate individual & system advocacy mission with an emphasis on persons who are underserved.
 - 4) Establish a state Independent Living Council to provide statewide policy direction.

- 5) Develop a Technical Assistance Network in conjunction with ATBCB.
- 6) Establish the Independent Living grant based on a progressive funding formula independent of the establishment grant
- 7) Establish an Independent Living Commissioner.

2. Implementation:

- a. Establish a commission made up of a majority of persons with disabilities to review the current act and develop detailed recommendations for change and reform.
- b. Reauthorization should be for three years.
- c. Sponsor regular White House conferences on disability priorities and issues.
- d. Develop a *waiver demonstration* program:
 - 1) States apply for all or part of their funding to be directed to their waiver program.
 - 2) Waiver must demonstrate accountability for qualitative services.
 - 3) System must have a component to train participants as systems change agents.
 - 4) System must demonstrate the ability to provide services that enhance social and economic independence and address lifelong need.
- e. Subsequent to the passage of the Americans with Disabilities Act, "Client Assistance Program Services" must be prepared for an increased demand from people with disabilities, and should be prepared to coordinate these issues. With broadened eligibility, the "Client Assistance Program Services" should have an increased all around capacity to serve all people with disabilities entering the system.

PROGRAM AND INTERAGENCY SYSTEMS

1. The Act must provide all services and supports necessary to ensure independence, productivity, and integration of people into the community. The Act should require linkage to obtain income maintenance, housing, and health care.
- 2 The Act should redefine outcome measures to correspond with the orientation toward lifelong careers and integrated independent community living. Case "closures" must be replaced with multiple approaches to assessing quality including:
 - a. Individual satisfaction.
 - b. Individual outcomes and measurements of:
 - Productivity - gainful employment, wages, benefits, and hours worked.
 - Independent living/independence.
 - Integration and involvement in the total community environment.
 - Other quality of life indicators.
 - c. The optimal match of services and supports to individual need.
 - d. Independent case coordination and independent third party evaluations.
 - e. Standards for service.
 - f. Employer measures such as satisfaction.
 - g. Efficiency - percentage of dollars spent on administration/services.
 - h. Appeals process and independent client assistance program.
 - i. State plan - public hearings, monitoring and oversight of the state plan.
 - j. Research, training, and technical assistance on evolving best practices.
3. Mandate that all individuals receiving services under the Act have an individualized service plan (*personal futures plan*) which is jointly developed and agreed upon by staff and the individual with a disability.
4. The Act should include a definition of consumer response accountability. *Consumer-responsive* is defined by factors such as: convenience; choice and selection; courtesy and prompt delivery of goods and services: continuity and reliability.
5. All services funded under the Act must be available on an ongoing basis, based on the needs of the individual using comparable benefits whenever possible.
6. Support services shall include all current Tide I services plus:
 - a. Training:
 - 1) Functional: Habilitation including •Daily living skills (Independent Living), •Mobility, and •Communications.
 - 2) Productivity: •Employment preparation/vocational, •Accommodations, •Careers. •Job coach (only if needed).
 - 3) Empowerment: Self, family, peer, representative, maximizing potential •Personal futures planning, and • Assertiveness skill.
 - b. Personal assistance/support.
 - c. Information and referral - Information on technology, services, benefits, rights, responsibility.

- d. Rehabilitation engineering.
- e. Mandate transitional services linkage with schools.
- f. Transportation.
- g. Family support
- h. Follow-up/follow-along.
- i. Postemployment services.
- j. Clinical research.
- k. Protection and advocacy (assistance in accessing services, advocacy, rights protection).
- l. Service coordination.
- m. Disability Allowance:
 - 1) Financial equalizer to offset increased costs of having a disability as needed, fair and reasonable.
 - 2) Currently supported through Family Support (cash subsidy/voucher).
 - 3) Complete adaptation of all environments and eliminating all barriers, until that level of equality is attained and disability allowance would compensate persons for increased costs associated with disabilities.

7. Establish a comprehensive, National and state to local office/individual counselor, electronic information and referral data base and state of the art communication system. This technology, available to every staff, must be accessible to people with disabilities and their representatives (families, significant others, advocates).

8. The Act must establish a commitment to early intervention and prevention-of-harm intensive training for professionals, peer counselors, and self-advocacy roles with new program design throughout education, social services, and health care systems.

9. Governance - the state agencies should be free standing with policymaking boards consisting of people with disabilities.

10. Create a mandated statewide planning council which would: a) plan and coordinate all services funded under the Act; b) identify duplication and gaps in services; c) provide input and review of state program and independent living state plans; d) provide input into policy development; e) centralize I & R services; f) collect data, analyze and report trends.

11. Provide leadership for innovation in policy and practice, advocate research and its popular dissemination, review and reform proposed personnel systems and training, spearhead media and public education.

12. Provide demonstration authority for innovation.

TECHNOLOGY

1. The Act must establish a right to the tools of access. Technology is neither one shot training, nor ongoing income subsidy. It presents the concept of "ongoingness." There is no category for this type of ongoing episodic support. Technology represents a new way of thinking, one that more accurately reflects the independent living movement/disability rights perspective. Eligibility questions that technology represents are a concrete embodiment of civil rights.

2. **Definitions:**

- a. **Assistive Technology Devices and Assistive Technology Services** - Use definitions from Technology Related Assistance Act of 1988.
- b. **Independent Living** - Independent Living is not an alternative to being vocationally feasible. Independent Living is the basic support services needed to live a self-directed life.
- c. **Independence** - Defined in terms of how much control you have over your environment not in the number of tasks that can be done without assistance. A person can be independent and still use technological assistance and personal assistance.
- d. **Consumer responsiveness:**
 - 1) Assessment should focus on abilities, oriented toward functional/situational/integration issues.
 - 2) Assessment and training, especially for jobs, should occur in integrated, appropriate settings.
 - 3) Establish *Non-Restrictive Environment* concept with no more federal funds for segregated programs and settings. It is not a continuum of services like LRE.
 - 4) Technology can and must be provided as a primary and singular service.
 - 5) Priority is given to using technology as part of the job site accommodation to return to former job without requirement for evaluation and retraining.

3. **Telecommunications:**

- a. Establish a priority for removal of communication barriers. The name of the ATBCB be changed to reflect recognition of importance of communication.
- b. Urgent action must be taken to assess the window of opportunity for adopting fully accessible, integrated, telecommunication technologies to *avoid the need for retrofitting*.

4. **NIDRR Research Program:**

- a. Establish an REC/RTC to study technology policy. The Center would :
 - study funding mechanisms for assistive technology with an I&R component
 - train on topics of national significance,
 - coordinate with state programs and with work funded under the Tech Act
 - establish the basis for the development of uniform approaches to cost-benefit analysis and cost-effectiveness analysis so these studies can be effectively compared.
- b. Establish a priority for mass marketing of accessible and adaptable designs and products.
- c. Mandate integration and joint funding of research activities among all national agencies (SSA, ADD, NIA, etc.)

5. **Funding:** Flexible funding options must be developed, including interagency cost sharing and private sector cost sharing.

PERSONNEL

1. Mandate a new model for personnel development based on a shift to an **Advocacy and Empowerment** paradigm. **The** Act should define **the** primary role of all "qualified personnel" as advocates. Personnel will become advocates who:

- a. **Are** knowledgeable of all resources available in the community.
- b. Possess organizational skills.
- c. Have the ability to empower leadership among individuals with disabilities.
- d. Have the ability to facilitate civic/community participation such as affecting community teams.

Minority View: Personnel practices of current system should be retained, updated, and expanded to meet growing demands.

2. Advocacy service/training must be included in Tide I language as "essential and appropriate service."

3. Establish *Advocacy Specialist* Personnel Model:

- a. Advocacy Specialist assist persons with disabilities to learn self-advocacy/system advocacy as well as helping to broker/manage community supports so persons with disabilities can reach their personal visions by gaining access to those supports available in the community.
- b. Advocacy Specialists work with and assist generic support systems to make their setting accessible to persons with disabilities (accessibility: attitudinal, physical environment, programmatic, technological).
- c. Redirect training of leaders and counselors from clinical/rehab model to advocacy/community broker model.
- d. Develop new curriculum/training programs for rehab personnel or integrate mem into current curriculums such as in the community organization-social change agents.
- e. Professional and consumer advocacy training curriculum must be state of the art and include:
 - 1) History of oppression and segregation of people with disabilities, the experience of disability in the culture including anti-discrimination awareness & orientation.
 - 2) Knowledge of federal/state statutes and policies, especially civil rights.
 - 3) System of federal, state and local structures, agencies and resources.
 - 4) Human psychology, counseling, case management, theory, skills and best practices.
 - 5) Community organizational skills including, social and political empowerment strategies.
- f. Institutionalize dissemination of best practice information through the Advocacy Specialists and fellowships.

4. Mandate and implement a consumer empowerment education repertoire:

- a. Directed at youth and adults, individuals, and families.
- b. Prepare persons with disabilities to be self-advocates and system advocates.
- c. Methods:
 - 1) Curriculum change for P.L. 94-142 to incorporate advocacy components.

- 2) Curriculum/experience change of nondisabled students, teachers, etc., in areas of disability awareness/career search/experiences *with* persons with disabilities.
 - 3) Incorporate into current Transition Programs.
 - 4) Establish and implement curriculum through independent, competency-referenced, value-based allied community agencies that respect and employ a consumer accountability model.
5. Provide Generic Community Supports:
 - a. Build awareness and incentives within generic community supports to achieve access and inclusion.
 - b. Impact on current training programs for people who lead and work in all of the support services.

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**REAUTHORIZATION OF THE REHABILITATION ACT CONFERENCE:
A COMPREHENSIVE VISION FOR THE 21ST CENTURY**

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