THE WHITE HOUSE

WASHINGTON

January 31, 1995

MEMORANDUM FOR DISABILITY POLICY REVIEW WORK GROUP CONVENORS

FROM: Carol H. Rasco, Assistant to the President for Domestic Policy

SUBJECT: Meeting Announcement

The second meeting of work group convenors of the National Disability Policy Review will be held on **WEDNESDAY, FEBRUARY 8, 1995, 3:00-4:00 p.m. in Room 211 of the Old Executive Office Building.**

At this meeting, we plan to review a final draft of the Guiding Principles which will be faxed to you in advance. We will also discuss the status of the inventory of programs serving people with disabilities.

Please contact Elisabeth Cohen at (202)456-5571 to RSVP and provide clearance information (date of birth).

Thank You.

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Judy Feder
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FACSIMILE TRANSMISSION

of the

Administration on Developmental Disabilities

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REMARKS:	

The following represents the collective thoughts and creative energies of Judy Heumann, Howard Moses, Susan Daniels, Liz Savage, Paul Miller, Andy Imp..., Speed Davis, Kate Warren and myself. It is meant to be a point of departure rather than a final product. Thank you! Bob Williams

The fundamental role of governments in respect to individuals with disabilities should be to assure the right of such persons (citizens?) to enjoy full inclusion and integration in the educational, economic, political, social and cultural mainstream of American society. In practical terms, therefore, governments must assure that people with disabilities have an equal opportunity to live as independently as possible; enjoy self-determination; make choices; and, to be be productive throughout their lives. It is, therefore, in the Nation's interest that public policies, programs, benefits and activities affecting such individuals be designed and implemented to:

o Provide strong, effective and fair enforcement of the Americans with Disabilities Act, Title V of the Rehabilitation Act, the Fair Housing Act Amendments, and the Individuals with Disabilities Education Act to help end discrimination against Americans with disabilities and strengthen our Nation's communities and economy.

o Strengthen the **capacities** of such persons and assure that needed services and supports are provided in a coordinated fashion which maximizes their control over their own lives and futures in the mainstream of American life.

o Assure that any assistance provided to such a person is carried out in an individualized manner, consistent with the unique strengths, resources, priorities, concerns, choices, abilities and capabilities of that individual.

o Support the efforts of families with children with disabilities to raise their sons and daughters at home and to include them in every facet of family and community life.

o Improve access to the assistance, technology and supports which enable these individuals to have greater control over their lives and contribute more fully to their home, family, school, work and community life.

o Assure that qualified individuals with disabilities have the opportunity to achieve equally effective results in all programs and activities by insuring such support is universally designed to meet the needs of the public and disability related needs as well.

o Make it pays for such citizens to work by creating incentives rather than disincentives to work and to pursue careers.

January 24, 1995

MEMORANDUM TO: Members of the National Disability Policy Review Team, Guiding Principles Workgroup

FROM: Bob Williams, Commissioner
Administration on Developmental Disabilities
Convener, Guiding Principles Workgroup

SUBJECT: Process and timeline for review of Guiding Principles

I am writing to update you on the status of a discussion draft of the Guiding Principles.

A subcommittee of the full workgroup has continued to work on refining the document per input from the December meeting. This draft will be shared with the conveners of each workgroup in a meeting scheduled for the first week in February.

Following the conveners' review, a draft will be faxed to each of you and shared with the advocacy community for additional discussion and comment. **The guiding principles workgroup may be convened prior to the full NDPRT meeting February 22 should comments received require further discussion.**

Members of the full policy review team will discuss and adopt a final version of the Guiding Principles document at the meeting scheduled for February 22nd.

Should you have any questions, please contact Kate Warren at (202)690-6120.

Also, please check this as to [illegible] before it goes out

Thanks, Kate

GUIDING PRINCIPLES for _____.

- This effort to develop a national disability policy is guided by the belief that national policy should promote the full inclusion and integration of P.W.O. in . . .
- Government's role: opportunity
- The individual's role: responsibility.
- Define the social contract / use term NEW Covenant?

The following represents the collective thoughts and creative energies of Judy Heumann, Howard Moses, Susan Daniels, Liz Savage, Paul Miller, Andy Imp..., Speed Davis, Kate Warren and myself. It is meant to be a point of departure rather than a final product. Thank you! Bob Williams

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o Make it pays for such citizens to work by creating incentives rather than disincentives to work and to pursue careers.

Draft materials toward a working set of "Guiding Principles" for the National Disability Policy Review

I. PRESIDENTIAL STATEMENTS

A. "three simple creeds: inclusion, not exclusion;
B. independence, not dependence;
C. empowerment, not paternalism" [1]
D. On increasing productivity and the important role of the public and private sectors in bringing people with disabilities into the work force and tapping their "knowledge and skills, their energy and creativity" as part of a workforce that faces an increasingly competitive international marketplace, see proclamation of September 30, 1994.[2]
E. On celebrating "our myriad differences" and acting on our "understanding that having a physical or mental disability is a part of the human experience"(i.e., destigmatizing disability status and reality), see proclamation on July 26, 1994.[3]
F. On the "Nation's commitment to remove any physical or attitudinal barriers that Americans with disabilities may still face," see proclamation 6612 of October 15, 1993.[4]
G. On increasing "the Nation's understanding and acceptance of people with mental illness," recognizing their need for a "broad array of treatment services," removing "the stigma of mental illness," and educating the public about "the availability and effectiveness of mental health treatment."[5]
H. On the capacity of 'millions of americans with disabilities 'to achieve independence and lead active, productive lives with the assistance of rehabilitation therapy, see proclamation 6596 of September 22, 1993.[6]

II. CONGRESSIONAL FINDINGS

A. Purpose of the ADA: "a clear and comprehensive national mandate for the elimination of discrimination against individuals

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[1] Gov. Clinton & Sen. Gore, Putting People First: how We Can All Change America 81-82 (1992).

[2] Presidential Proclamation on National Disability Employment Awareness Month, 1994 (Sept. 30, 1994).

[3] Presidential Proclamation on Anniversary of the ?Americans with Disabilities Act, 1994.

[4] Presidential proclamation 6612, White Cane safety Day, 1993, Oct. 15, 1993.

[5] Presidential Proclamation 6603 of October 5, 1993, Mental Illness Awareness Week, 1993.

[6] Presidential Proclamation 6596 of September 22, 1993.

with disabilities"

1. with "clear, strong,consistent, enforceable standards addressing [such discrimination..."

2. with "the Federal Government play[ing] a central role in enforcing the standards established in this Act on behalf of persons with disabilities"[7]

B. Key Findings enumerated in the ADA

1. "the Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals"[8]

2. the "continuing existence of unfair and unnecessary discrimination and prejudice denies people with disabilities the opportunity to compete on an equal basis and to pursue those opportunities for which our free society is justifiably famous and cots the US billions of dollars in unnecessary expenses resulting in dependency and nonproductivity."[9]

C. Basic Findings in Recent Congressional Reauthorizations: "Disability is a natural part of the human experience and in no way diminishes the right of individuals --

1. live independently;
2. "(B) enjoy self-determination;
3. "(C) make choices;
4. "(D) pursue meaningful careers; and
5. "(E) enjoy full inclusion and integration in the economic, political, social, cultural, and educational mainstream of american society."[10]

III. OTHER STATEMENTS BY ADMINISTRATION LEADERS

A. Vice-President Gore's ADA speech

B. Carol H. Rasco's article, "Empowering People with Disabilities and their Families"[11]

IV. REPORTS OF FEDERAL AGENCIES AND ADVISORY COMMISSIONS

A. universality of equal opportunity: "'policies that guarantee equal opportunity for all individuals with

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[7] The Americans with Disabilities Act, 42 USC sec. 12101 (b)(1)-(3). (July 26, 1990).

[8] Id. 42 USC sec. 12101 (a)(8).

[9] Id. sec. 12101(a)(9).

[10] E.g., Technology-Related Assistance for Individuals with Disabilities Amendments of 1994, 29 U.S.C. sec. 2201(a).(copy of Congressional findings attached).

[11] Exceptional Parent 47-49 (June 1994).

disabilities, regardless of the nature and severity of the disability" &

B. the theme of empowerment: "to achieve economic self-sufficiency,
independent living,
and inclusion and integration into all aspects of society."[12]

C. Query: how do we translate such broad principles into defined policy-oriented guiding principles?

V. Miscellaneous

A. Individualization of treatment/response

B. Reduction of redundant eligibility determinations

C. The principle of the least restrictive alternative

D. See Principles Guiding the Drafting Process [of Model State Legislation][13]

Prepared by Stan Herr
December 12, 1994

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[12] Mission of the National Council on Disability, reprinted in NCD, Making Health Care Reform Work for Americans with Disabilities 45 (July 26, 1994).

[13] Bruce Sales, A. Matthew Powell, Richard Van Duizend et al, Disabled Persons and the Law: State Legislative Issues (1982). This book was published by the ABA Commission on Mental disability and the Law based on federally financed research. Although the "maximize potential" standard is quite expansive, the other principles find considerable support in federal legislation, policy, and judicial opinion.

PUBLIC LAW 103–218 [H.R. 2339]; March 9, 1994

TECHNOLOGY-RELATED ASSISTANCE FOR INDIVIDUALS WITH DISABILITIES AMENDMENTS OF 1994

For Legislative History of Act, see Report for P.L. 103–218 in U.S.C.C. & A.N. Legislative History Section.

Act to revise and extend the programs of the Technology-Related Assistance for Individuals With Disabilities Act of 1988, and for other purposes.

Be it enacted by the Senate and House of Representatives of e United States of America in Congress assembled,

CTION 1. SHORT TITLE; TABLE OF CONTENTS.

(a) SHORT TITLE.—This Act may be cited as the "Technology-lated Assistance for Individuals With Disabilities Act Amend-nts of 1994".

(b) TABLE OF CONTENTS.—The table of contents for this Act as follows:

C. 2. REFERENCES.

Except as otherwise specifically provided, whenever in this an amendment or re [is expr [in ms of an amendment or a repeal of, a section or other provision, the reference shall considered to be made to a ion or other provision of the hnology-Related Assistance for Individuals With Disabilities Act

SEC. 3. FINDINGS, PURPOSES, AND POLICY.

(a) SECTION HEADING.—Section 2 (29 U.S.C. 2201) is amended by striking the heading and inserting the following:

"SEC. 2. FINDINGS, PURPOSES, AND POLICY.".

(b) FINDINGS.—Section 2(a) (29 U.S.C. 2201(a)) is amended to read as follows:

"(a) FINDINGS.—The Congress finds as follows:

"(1) Disability is a natural part of the human experience and in no way diminishes the right of individuals to—

"(A) live independently;

"(B) enjoy self-determination;

"(C) make choices;

"(D) pursue meaningful careers; and

"(E) enjoy full inclusion and integration in the economic, political, social, cultural, and educational mainstream of American society.

"(2) During the past decade, there have been major advances in modern technology. Technology is now a powerful force in the lives of all residents of the United States. Technology can provide important tools for making the performance of tasks quicker and easier.

"(3) For some individuals with disabilities, assistive technology devices and assistive technology services are necessary to enable the individuals—

"(A) to have greater control over their lives;

"(B) to participate in, and contribute more fully to, activities in their home, school, and work environments, and in their communities;

"(C) to interact to a greater extent with individuals who do not have disabilities; and

"(D) to otherwise benefit from opportunities that are taken for granted by individuals who do not have disabilities.

"(4) Substantial progress has been made in the development of assistive technology devices, including adaptations to existing equipment, that significantly benefit individuals with disabilities of all ages. Such devices can be used to increase the involvement of such individuals in, and reduce expenditures associated with, programs and activities such as early intervention, education, rehabilitation and training, employment, residential living, independent living, recreation, and other aspects of daily living.

"(5) Most States have technology-related assistance programs carried out under this Act. In spite of the efforts made by such programs, there remains a need to support systems change and advocacy activities in order to assist States to develop and implement consumer-responsive, comprehensive statewide programs of technology-related assistance for individuals with disabilities of all ages.

"(6) Notwithstanding the efforts of such State technology-related assistance programs, there is still a lack of—

"(A) re urces to pay for istive nology devi and assistive technology servi ;

"(B) trained personnel to a ist individuals with

Empowering People with Disabilities and Their Families

by Carol H. Rasco

I come to you to express my deep commitment, and that of the Administration, to the empowerment of people with disabilities.*

Those of you who work in this field—whether as volunteers, professionals or family members—boost our determination and our capacity to resolve the tremendous challenges that remain before us. Your dedication and compassion inspires us to embrace the responsibility of meeting them.

As a parent who worked exclusively in this field as a volunteer until my son was seven, and who now works as a policy-maker, I want to tell you about some of the ideas and individuals that inspire me in my daily work. Although I will focus on health care reform, our reform agenda also extends from education reform to welfare reform, from safer streets to safer transitions to adulthood for all our youth.

Carol Rasco and son Hamp celebrate his 20th birthday. (Photo: Charles Archambault/Archambault Photography)

The White House Domestic Policy Council coordinates the efforts of the Administration, Cabinet secretaries and other federal agencies involved with the development of every aspect of our nation's domestic policy. As director of the Council's day-to-day work, I bring a strong determination that *all children shall be empowered to develop to their fullest potential.* To meet this crucial goal, our children need each of us to believe in them, and we as parents need the opportunities to nurture their growth.

As President Clinton recently stated, "Having a disability does not diminish one's right to participate in all aspects of mainstream society." On the Domestic Policy Council we take that right very seriously. Working together in public-private partnerships, we are responding to the President's call to "craft policies of inclusion, independence and empowerment that will inspire positive changes in this country and in nations around the world."

Health care reform is an indispensable part of that mission. The President's health care plan is a dramatic advance for people with disabilities and their families. Here's why:

- It guarantees universal coverage for all Americans, and the peace of mind of having health care that is always there.
- It outlaws the current insurance practices of excluding people with pre-existing health or disability conditions, or of jacking up your rates if you get sick or become disabled.
- It forbids insurance companies from picking only the lowest-risk individuals and families, and rejecting others.
- It builds on today's private insurance system, which is primarily employer-based, while making insurance more affordable for the self-employed and subsidized for the unemployed. As a result, no one will be uninsured, even if they or members of their family experience a disability, injury or sickness.
- It offers a nationally uniform and comprehensive benefit package—in contrast to some of the other legislative proposals—that includes a range of preventive services, doctor and hospital visits, outpatient rehabilitation, home health care, adapted durable medical equipment (including orthotic and prosthetic devices and training in their use), mental health services, and many other essential services.

Furthermore, under Senator Edward Kennedy's proposal—now in congressional committee markup—outpatient rehabilitation services would be available to those who need them to restore capacity or minimize limitations as a result of illness, injury, "disorder or other health condition." And to maintain functioning or to prevent or minimize deterioration, rehabilitation services would be provided through a four-step process—initial evaluation and periodic oversight by a qualified rehabilitation health professional; design of a maintenance or prevention program; instructions for the patient, family members or support personnel to carry out the program; and patient reevaluations.

- It provides a major expansion of long-term care coverage by adding home- and community-based services for people with severe disabilities, regardless of age or income. With a projected three million people with dis-

* *This article is a revised and expanded version of remarks delivered by Ms. Rasco to the Arc Governmental Affairs Seminar, held in Washington, DC, on March 21, 1994. Nonprofit and disability organizations may freely make copies of this article for their members' information.*

abilities and their families benefiting from this new program, this coverage allows people with disabilities to live in their own homes—with their families, where appropriate—and to enjoy fuller and more satisfying lives.

- It adds significant civil rights protections for the enjoyment of health care benefits, consumer involvement in the design of the new home- and community-based services for individuals with disabilities, and health care "report cards" so that families can determine the health plan that best fits their needs and reward that plan with their membership.

The disability rights movement can play a critical role in this drive for universal coverage. On May 2nd, I was delighted to be with the President as he hosted 125 leaders of the disability community in a tremendously enthusiastic rally for health care reform. As the President emphasized: "This is a battle that you may be able to lead for the rest of America... And so I ask you: Be an agent of change, an agent of empowerment. Never forget that you are carrying on your shoulders not only your cause, but ours as well. You can break through to those members of Congress. You can do it." From the White House, these leaders were joined by about a thousand others who marched across the Memorial Bridge to rally at the Lincoln Memorial; then, on to lobby on Capital Hill.

Now is the time to guarantee health security for ourselves, for our children and for the generations to come. Without secure health coverage, too many of us are not free to change jobs, move to a different location or venture from disability rolls to payrolls. Without that security, employers may be reluctant to hire a person with a disability or a person with a family member who has a disability.

These basic principles unite us. But it is our common love for our families that propels us to act.

Early in my son's life, a physical therapist who had dedicated her long career to helping young children with disabilities shared with me the words of essayist and poet Joseph Addison: "Everyone must have something to do, someone to love, something to hope for."

I am constantly reminded of those words, not only for my son, Hamp, but for all the people with whom I've worked. In our quest to empower people, we must strive to fulfill these ends at each stage in life. In this process, we have myriad questions to ask and actions to take.

What do persons with disabilities have to do? For a young child, is a preschool program or other early intervention available? For a school-age child, is school relevant, safe and effective? Are our schools and transitional programs teaching both how to make a living and how to live? And, for adults, is there a job, day activity or voluntary service that satisfies and excites? As President Clinton said in Memphis last November: "I do not believe we can repair the basic fabric of society until people who are willing to work have work. Work organizes life. It gives structure and discipline to life. It gives meaning and self-esteem to people who are parents. It gives a role model to children... We cannot, I submit to you, repair the American community and restore the American family until we provide the structure, the value, the discipline and the reward that work gives." Those powerful thoughts are particularly apt for our citizens with disabilities who, too often, experience high rates of unemployment and underemployment.

What do persons with disabilities have to hope for? And what do we who love them have to hope for? Linda Charlton, the mother of a two-year-old daughter with Down syndrome, recently described her goals for her Katie before a superb and productive meeting of the President's Committee on Mental Retardation:

> "First, we want her to feel loved... to give her a sense of high self-esteem so that she can experience life with confidence. She is a very social child and while I think she has the capacity to make many friends, I wonder how other children will accept her. We envision her attending public schools, at least for the most part, and one day we hope to see her graduate from high school. There's even a part of us that hopes she'll continue her education after that... I wonder if she'll ever get married... if she doesn't, I hope at least she has a companion to enjoy life with. And if we could, we'd like to see her remain as happy as she is today... Our Katie—who loves people, music, dogs, rain, sunshine, swings, cookies, apricots, baths and the color red."

These are dreams and feelings to which any parent can relate. Many of them were fulfilled for me when my son was asked last year by the members of his high school graduating class to give one of the commencement addresses. I will never forget that moment, nor will Hamp. Here was the young man whom we were once told would not survive or if he passed the hurdle of his first days, would have to be institutionalized. But Hamp defied those predictions, living at home and attending school with his non-disabled peers. This is the speech that he wrote, on his own, politely declining his mother's offer of help. Hamp said that this was his speech to give:

> "Hello, my name is Hamp Rasco. I am pleased to share with you what attending Hall High has meant to me.
>
> "I enjoyed the pep assemblies and the band. I enjoyed talking with friends in the cafeteria and going out into the community with my CBI class.
>
> "After graduation I plan to find a job in the community where my social skills can be put to use. This is important to me because I want to make new friends with all kinds of people.
>
> "I would like to encourage other students with special needs to never give up, work hard to do a good job and be proud and happy about what you do at school.
>
> "I want to thank Dr. Anderson and the vice principals for their support of my program. I want to tell Ms. Chapman and Mr. Smith how much I appreciate all the work

they have done on my behalf and for all students with special needs. And I also thank Ms. Yates. And, finally, I especially want to thank my parents for believing in me and always encouraging me to be all that I can be. I really hate to leave all my friends at Hall, but I must move on.

"Thank you. Good evening."

Like Hamp, we must all move on. Great challenges lie ahead, indeed. And as you well know, they are not limited to health care reform. From the White House to your house, we must work together. We need to reassure the countless young people like Hamp across this country that they will always have health insurance, that they can have jobs and that they are an essential part of life in our communities. For surely, to be whole and part of whole communities, people deserve something to do, someone to love and something to hope for.

The leaders of the disability community are campaigning to achieve these goals and objectives. I sincerely want to thank all those leaders, including Paul Marchand and the rest of Arc's Government Relations staff, for their hard work in fighting to bring health security to every American. In addition, I commend the 100 sister organizations united in the Consortium for Citizens with Disabilities for their steadfast support. Now, we must intensify those efforts. We must each tell our personal stories so that members of Congress have before them the human faces of health care reform. We need each of you to help seize this moment of opportunity to *guarantee private insurance for all our citizens—coverage that offers choice, comprehensive benefits and freedom from unfair and exclusionary insurance practices.*

I believe that a new day has dawned for America's citizens with disabilities and for all our people. We won't always succeed and we won't always be able to do everything that we want. But with your energy and resolve, we can have health security now. And I can promise you this: we will never relent in our effort to give every person a chance to develop—fully. Because, at the end of Bill Clinton's second term, at the start of the third millennium, I want to be able to say to Hamp Rasco and Mary-Margaret Rasco and to all of America, with a clear conscience and full heart—"We did our best." And for all our children's sakes, I want each of us to be able to look at one another and say—"We did our best."

Carol H. Rasco is the Assistant to the President for Domestic Policy. In this capacity, she is President Clinton's chief domestic policy adviser, coordinating the staff of the White House Domestic Policy Council. She is the mother of Mary-Margaret Rasco and Hamp Rasco.

warranted imposition. Chapter 8 presents a discussion of the protections that should be afforded to developmentally disabled persons in two very specialized areas — the criminal and juvenile justice systems. Some developmentally disabled individuals, as well as some individuals in the population-at-large, will come in contact with one or both of these systems. But because of special vulnerability, disabled persons are often less equipped than other individuals to enjoy the full rights that the law provides to alleged offenders. This chapter addresses that concern and presents model statutes to provide appropriate protections. The final chapter contains a discussion of advocacy for developmentally disabled persons, an essential service if these individuals are to enjoy, to the fullest, their rights and the appropriate provision of all other services.

It should be noted that the materials contained within this volume both reflect our judgments as to the most important topics to be considered as well as the resources available for this task. Some topics were excluded because they were not state legislative issues. Adequate transportation is a good example. This issue has been largely pursued within the context of federally subsidized mass transit programs and, as such, is primarily a federal issue which is not amenable to state legislative action. The issue is discussed, however, in Chapter 3 on eliminating environmental barriers, to the extent it impacts upon accessibility. Estate planning and will drafting techniques are other examples of topics outside of the scope of the project. While these issues involve state law, and are important to developmentally disabled persons and their parents, they are not problems which can be addressed by legislation and, thus, they were excluded.

The project was also guided in its selection of topics by a need to avoid duplication of the previous efforts of others. Some topics such as confidentiality of records[6], and experimentation on human subjects,[7] have already been addressed by other studies. Thus we declined to deal with these issues. This is not to argue that the work performed by others to date on these topics is definitive. Rather, we unfortunately had to conclude that further studies of these topics would not be feasible given the level of financial resources that we had to support our efforts. Finally, at least one area of legislation, the rights of disabled persons in residential facilities, revealed adequate legislative models among existing state statutes. Because of this finding, the decision was made not to develop a detailed chapter including model legislation. The Appendix does present, however, a review of existing state statutes on this topic which will allow the reader to easily identify those states which provide the most comprehensive and appropriate protections.

Principles Guiding the Drafting Process

Because of the diversity of the topics tl ; needed to be addressed, and because of the concern the staff, the advisory board and the consultants shared for safeguarding the rights of developmentally disabled persons and for assuring them equal access to quality services, consistent with the philosophy and program of P.L. 94-103 and other pertinent law, we identified certain principles that guided all our drafting efforts. These were:

(1) Each Individual Should Be Given The Opportunity To Maximize His or Her Potential And Fully Develop His or Her Abilities. Every person has some potential which can be developed with proper education and training. Because of this fact, services should be provided whenever needed so that this potential can be fully realized. Control over the individual should never be substituted for adequate service delivery. As applied to developmentally disabled persons, this principle requires that these individuals should have access to comprehensive services designed to maximize potential and minimize handicaps. In addition, the services should be designed to develop the basic intellectual and personal self-help skills necessary to function in the least restrictive setting possible and to function within the larger community with the least possible supervision. These self-help skills should include personal care, housekeeping skills, money handling, use of transportation, vocational skills, recreational skills, adaptive interpersonal behavior and knowledge about access to other services. The absence of such services will often force a developmentally disabled person into an unproductive and unnecessarily dependent role. In fact, past experience shows that, in their absence, society will resort to segregative incarceration, a denial of the most fundamental rights of the developmentally disabled individual.

(2) Developmentally Disabled Persons Should Be Provided With As Normal An Environmental And Experiences As Possible. There should be the fullest opportunity for normalizing experiences in which programs and services assist developmentally disabled persons to become fully integrated into the general society. Since self-help and acqui-

[6] See CONTRACT RESEARCH CORPORATION, THE CONCEPTUAL FRAMEWORK: A REPORT ON THE SOCIOLOGICAL ISSUES RELATED TO THE PROTECTION OF CONFIDENTIALITY AND THE RIGHT TO PRIVACY OF DEVELOPMENTALLY DISABLED PERSONS (1977); CONTRACT RESEARCH CORPORATION, FEDERAL REGULATIONS: CONFIDENTIALITY AND THE RIGHT TO PRIVACY OF PERSONS WITH DEVELOPMENTAL DISABILITIES (1977) and CONTRACT RESEARCH CORPORATION, MODEL STATE CODE: PRIVACY ACT FOR THE DEVELOPMENTALLY DISABLED (1977). These studies were prepared for the U.S. Department of Health and Human Services, Bureau of Developmental Disabilities.

[7] The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, created by Pub. L. 93-348. After considerable study, the Commission's recommendations published in 43 Fed. Reg. 11328 (March 17, 1978) have resulted in proposed regulations on the subject. See 43 Fed. Reg. 53950 (November 17, 1979).

sition of interpersonal skills, education, training and social adjustment can most effectively occur within a normalized environment, programs and services should also take place, as much as possible, in normal settings. Such settings will increase the interaction between developmentally disabled and non-developmentally disabled persons, thereby providing appropriate role models in social, self-help, and employment skills, while fostering the maximization of individual potential. This interaction also will help non-developmentally disabled individuals develop appropriate attitudes and acceptance of disabled individuals.

Services also should be delivered, insofar as possible, within the generic systems of service delivery in the community, rather than within specialized systems which may tend to isolate developmentally disabled persons and exaggerate differences. Generic service delivery systems (e.g., education, medical care, vocational training, recreation) already serve a highly diverse range of persons and needs. But, because of the tradition of segregating developmentally disabled persons from the mainstream of society, many such services have not accomodated these individuals' needs. Thus, adaption of generic service systems may be required to overcome past exclusionary practices and assumptions. The primary thrust must be to ensure that all generic services are flexible enough to accommodate the needs of developmentally disabled persons so that special services for these individuals will be exceedingly rare. For instance, education and training should be provided within the regular classroom or work situation unless the condition of the person makes it inappropriate to meet the person's developmental needs in this manner. Employment and economic productivity within the regular work force also should be maximized. For those who cannot enter the competitive labor market, sheltered workshops or daytime activities should be provided. Activity and productivity are a basic part of our lifestyle. Appropriate recreation and leisure activities should be available in the community. Finally, architectural and transportation barriers should be removed to maximize mobility within the community.

This principle further requires that developmentally disabled children be kept within their families when the developmentally disabled persons' needs can best be met in the home environment. This should aid in appropriate emotional development. Where alternative arrangements are required, they should be as homelike as possible with continued familial interaction encouraged. For adult developmentally disabled individuals, housing should reflect normal residential patterns to the extent possible and should be located within residential areas. Zoning restrictions should be removed when they limit this possibility.

(3) When Restrictions Must Be Placed On A Developmentally Disabled Person, The Alternative Which Is Least Restrictive Or Intrusive, Consistent With The Individual's Needs, Should be Imposed. People should be free to live as they please and pursue their own interests as they see fit. One individual's interest may, however, conflict with the communal interest or the interest of other individuals. Thus, some restrictions on individual freedom may be justified. There is a tendency, however, for those in power to impose broader restrictions than are necessary to meet communal interests. Where there are communal interests which may justify the regulation of individual conduct, these interests should be clearly identified so that impermissable interests can be rejected as the basis for differentiation.

Thus, where the individual cannot effectively participate in the systems of generic service delivery, he or she should receive specialized services or special adaptations of generic services based on an individual determination of the person's abilities and needs, so that the service alternative chosen is that which is least restrictive to the individual's rights. Placement in specialized services, generally, should be seen as temporary and should be accompanied by prescriptions to generic systems concerning adaptations needed in such systems to permit appropriate services to developmentally disabled persons. In addition, the delivery alternatives chosen should be periodically examined to assess the appropriateness of the choice given current needs and the availability of other alternatives. Restrictions should be maintained only where more informal, less coercive alternatives cannot achieve the identified needs.

(4) The Individual Shall Have Maximum Freedom of Choice Within His or Her Capacity And Within The Limitations Placed Upon All Persons By The Law. Although all persons are born dependent upon others, through the normal process of socialization, they become more responsible for themselves and make their own decisions about their lives. Unfortunately, this approach has not characterized the habilitation of persons with developmental disabilities. The traditional treatment of such persons has been characterized by paternalism and continued dependency.

Developmentally disabled persons should be encouraged to be independent and make their own decisions about their lives. Thus, they should participate as fully as possible in all decisions which may affect them. As noted above, this independence and decision-making ability can be fostered by normalization and maximizing individual potential.

Not all developmentally disabled persons will be able to function on their own, however. Some will need some degree of control and substituted decision-making. Yet "third-party consent" in lieu of personal decision-making allows the substitution of hidden agendas by other persons and should be carefully scrutinized. Where informed decision-making and consent are not possible by a

developmentally disabled person, no person with a potential conflict of interest should be allowed to make these substituted decisions.

(5) The Law Should Be Used To Recognize The Equality of Developmentally Disabled Persons With Other Citizens. Developmentally disabled persons, like all other citizens, should be entitled to enjoy their personal and civil rights. For example, certain rights are basic to our functioning and are taken for granted by most persons including the right to procreate, marry, contract, make a will, vote, travel, and enjoy one's privacy. Yet, in many instances, states have imposed restrictions on these basic rights where a person is identified as being mentally ill or developmentally disabled. Yet, placing categorical disqualifications and restrictions on groups of individuals because of a label is unconscionable since most often we are unable to predict ability and performance based upon that label. Rather, there should be clearly specified behavioral standards which relate to the determination being made. For example, what standards of competency should be required to marry, or to make a testamentary disposition? These serve different purposes and, thus, should have different standards that are functionally related to the objectives being sought. Relatedly, discrimination against developmentally disabled persons in other areas (*e.g.*, employment, housing, insurance) must be stopped.

(6) Developmentally Disabled Persons Should Be Provided Advocacy Assistance When Needed To Protect And Effect The Exercise And Full Enjoyment of Their Rights. Many developmentally disabled persons will not be able to protect their rights or acquire the services they need without the assistance of an advocate including an attorney where appropriate. These rights and services mean little if they remain unavailable to those who do not have the ability to exercise or utilize them. Thus, advocacy assistance is essential. Advocates should represent the interests of the developmentally disabled person and should be independent of all service providers and other potential conflicts of interest. In addition, they should have the broadest access to information that is essential for pleading their client's interests.

Although these principles do not cover all of the issues that needed to be addressed in our work, they did provide a necessary framework from which we approached our drafting efforts. Other principles that guided the drafting of specific chapters are presented within them.