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Ideology and Independent Living: Will Conservatism Harm People with Disabilities?

By ANDREW I. BATAVIA

ABSTRACT: The prospect of a conservative revolution has raised the anxiety of the predominantly liberal disability leadership. Whether the diverse disability community shares the policy objectives of the leadership, and its concern over the conservative agenda, is not clear. This article considers four major branches of the conservative movement—fiscal conservatism, the federalist movement, social and religious conservatism, and libertarianism—and their compatibility with the independent living movement, a social movement supported by most people with disabilities. It concludes that the two social movements have several consistent tenets, such as individual responsibility, personal and economic freedom, and self-reliance. Conversely, liberal policies, which tend to encourage dependency, appear in direct conflict with the independent living philosophy. The Americans with Disabilities Act is examined as a disability policy that is largely consistent with conservative principles. The article concludes that, to achieve their policy goals, people with disabilities should seek representation on both sides of the political aisle and should develop proposals that will be acceptable to conservatives and moderates as well as liberals.

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NOTE: The views expressed are solely those of the author and do not necessarily represent the positions of McDermott, Will & Emery or any other organization with which the author is affiliated. The author thanks Ruth Brannon, Gerben DeJong, Lex Frieden, Bill Johnson, and his wife, Cheryl Nicholson Batavia, for their valuable comments on this article.

THE 1994 mid-term elections, in which Republicans won majorities in both houses of Congress, marked a conservative political shift in this country.¹ Whether it constitutes a short-term shift or a political sea change, much as the election of Franklin D. Roosevelt galvanized a liberal revolution, remains to be determined at the time of this writing. We will have a better sense of this after the 1996 elections. Even if President Clinton is reelected, it is arguable that the conservative trend has continued, because he chose largely conservative themes for his campaign. If we are in the midst of a conservative revolution, the long-term implications will be profound for all aspects of policy in our nation, including disability policy.

The leaders of the disability community, most of whom are advocates committed to liberal ideology, were

1. Throughout this article, the terms "conservative" and "liberal" are used in the modern sense. "Conservatism" is used to refer to a political ideology with the fundamental tenets that the role of government should be strictly limited and that personal responsibility and individual freedom should have primacy in formulating public policy. The term "liberalism" is used to connote a political ideology with the fundamental tenets that there should be collective responsibility for the social and economic problems of our citizens and that government has a vital role in solving such problems. The term "moderate" is used to refer to intermediate positions that recognize a legitimate role for government that is neither as extensive as that demanded by liberals nor as limited as that demanded by conservatives. It should be noted that "conservative" is not used to connote resistance to changes in the status quo. Either conservative or liberal policies can be reactionary, in the sense of resisting progressive change, depending upon the existing state of national policy.

deeply concerned over the Republican takeover of Congress and its implications for their policy agenda. There is evidence that most people with disabilities adhere to the general philosophy of the independent living movement,² which is supported broadly by disability leaders across the political spectrum. It is not clear, however, that a majority of the disability community also supports the liberal policies advocated by the majority of the disability leadership.

The disability community is not the monolith that is often portrayed in policy debates. Although people with disabilities, on average, are poorer and less employed than the overall population, they are also extremely diverse with respect to virtually all social and economic characteristics.³ A recent poll indicates that, while 48 percent of people with disabilities consider themselves Democrats, about as many—44 percent—say that they are not Democrats; 25 percent are Republicans; and 19 percent are independents.⁴ A legitimate question that must now be asked is, Which policies are most consistent with the independent living goals of the disability community, and how will such policies affect individuals with disabilities?

This article considers whether the conservative movement and the independent living movement are inherently incompatible, as suggested by many liberal disability leaders, or if

2. Louis Harris and Associates, *N.O.D./Harris Survey of Americans with Disabilities* (New York: Louis Harris and Associates, 1994).

3. Ibid.

4. Louis Harris and Associates, *N.O.D./Harris Survey of Americans with Disabilities* (New York: Louis Harris and Associates, 1996).

the two movements can accommodate each other for the benefit of people with disabilities. It examines the fundamental tenets of both movements, and whether those tenets and the policies purported to further them are philosophically consistent. Finally, it considers whether independent living goals can be achieved through conservative means, based on an analysis of the Americans with Disabilities Act of 1990 (ADA). The objective is to transcend superficial political labels and partisan rhetoric to discern the true political interests of people with disabilities.

TENETS OF THE INDEPENDENT LIVING MOVEMENT

The independent living movement⁵ is a social movement that was initiated in the early 1970s largely by people with disabilities who sought to eliminate the barriers that prevent them from living independently and productively in their communities.⁶

5. The independent living movement is also often referred to as the disability rights movement. Whether these are two separate but overlapping social movements or two terms for the same movement is a matter of debate. Discussion about the independent living movement typically focuses specifically on environmental barriers and the ability of individuals with disabilities to live in their communities. Discussion about the disability rights movement typically focuses more broadly on the autonomy of individuals with disabilities to pursue their goals, whatever those goals might be.

6. Gerben DeJong, "Independent Living: From Social Movement to Analytic Paradigm," *Archives of Physical Medicine and Rehabilitation*, 60:435-46 (1979); idem, *Environmental Accessibility and Independent Living Outcomes: Directions for Disability Programs and Research* (East Lansing: Michigan State University, University Center for International Rehabilitation, 1981).

Like the civil rights movement on which it was based in part, the independent living movement was conservative in the sense that it relied upon concepts of self-help, self-reliance, and personal responsibility. The initial stage of the movement focused less on redistributing resources than on undoing the wrongs that historically had been perpetrated on people with disabilities. For example, disability rights advocates lobbied successfully for implementation of Title V of the Rehabilitation Act of 1973, which requires the federal government and its contractors to make their programs and services accessible to people with disabilities.

It was soon after its initial stage that the movement took on its current, predominantly liberal character, demanding substantially increased government involvement. This focus on government as a solution is understandable. People with disabilities consistently have had the highest rate of unemployment of all groups in our society—a jobless rate of 75 percent.⁷ They have been subject to the most pernicious discrimination of all groups, with the possible exception of African Americans.⁸ Only government has the authority and capacity to prohibit discrimination and significantly redistribute resources.⁹ Reliance on social philanthropy, which was the primary

7. Harris and Associates, *N.O.D./Harris Survey of Americans with Disabilities* (1994).

8. Frank Bowe, *Rehabilitating America: Toward Independence for Disabled and Elderly People* (New York: Harper & Row, 1980).

9. Andrew I. Batavia, "Relating Disability Policy to Broader Public Policy: Understanding the Concept of Handicap," *Policy Studies Journal*, 21(4):735-39 (1993).

approach to addressing the needs of people with disabilities through much of this century, did nothing to eliminate discrimination and created an unhealthy dependence on private sector charities.

Thus it appears clear that some form of government intervention is necessary to address the needs of people with disabilities in a dignified manner, particularly for those with limited resources and little family support. Many face substantial difficulties in seeking independence due to (1) their functional limitations, which may to some extent inherently limit their capacity to work;¹⁰ (2) environmental barriers that further limit their options to obtain employment and live in their communities;¹¹ and (3) attitudinal barriers that result in active discrimination against them.¹² The powers of the government represent a potent tool to eliminate barriers and to provide subsidies necessary for many people with disabilities to live.

Conversely, misguided government policies can replace an unhealthy dependence on charity with an equally unhealthy dependence on

10. It is the author's belief that the vast majority of people with disabilities are capable of gainful employment, irrespective of their functional limitations, and that the primary impediments to their obtaining and maintaining a job are environmental barriers, such as inaccessible workplaces, and attitudinal barriers, such as employer prejudice against disability. Experience has demonstrated that people with very significant functional limitations, such as high-level quadriplegia and respirator dependence, have been able to work if given appropriate training and support.

11. DeJong, *Environmental Accessibility and Independent Living*.

12. Bowe, *Rehabilitating America*.

government. Neither form of dependence is consistent with the goals of the independent living movement or the long-term interests of people with disabilities. For example, the vast majority of the over 7 million beneficiaries of the federal disability programs stay on the disability rolls permanently; only 2 percent ever leave the programs through gainful employment.¹³ While the policies of such programs may protect people with disabilities from the insecurity of the jungle, they also may offer the security of the zoo, trapping them in a life of dependence and denying them freedom to achieve their highest potential.

Finally, the fact that a government role is essential in meeting the needs of people with disabilities does not necessarily mean that the federal government must take the lead or that disability programs must continue to be designed as they have been historically. Thus far, most disability programs in this country have had only modest success in achieving their goals; most have failed in assisting people with disabilities to achieve true independence through employment.¹⁴ Despite hundreds of billions

13. L. S. Muller, "Disability Beneficiaries Who Work and Their Experiences Under Program Work Incentives," *Social Security Bulletin*, 55(2):2-19 (1989); Carolyn L. Weaver, "Privatizing Vocational Rehabilitation: Options for Increasing Individual Choice and Enhancing Competition," *Journal of Disability Policy Studies*, 5(1):53-76 (1994).

14. Edward Berkowitz, *Disabled Policy: America's Programs for the Handicapped* (New York: Cambridge University Press, 1987); General Accounting Office, *Social Security: Increasing Number of Disability Claims and Deteriorating Services*, report to the Chairman, Committee on Finance, Senate, U.S. Congress,

Hypertension

Continued from previous page

■ **Go easy on the NSAIDs.** Regular use of non-steroidal anti-inflammatory drugs (NSAIDs) may boost blood pressure, particularly in older people. They may also blunt the action of certain antihypertensive drugs, particularly beta-blockers. Over-the-counter NSAIDs include ibuprofen (*Advil*, *Motrin-IB*) and naproxen (*Aleve*); there are also prescription versions of those pain relievers and many others that are commonly used for arthritis. Use NSAIDs regularly only when the benefits clearly outweigh the risks—and after first trying safer alternatives, such as acetaminophen (*Tylenol*, *Panadol*).

The big payoff

Making all those lifestyle changes isn't easy, and some of the blood-pressure reductions may seem inconsequential. But researchers estimate that every decline of 2 mm Hg of diastolic pressure typically lowers the risk of coronary disease by 6 percent, the risk of stroke and transient ischemic attack, or near-stroke, by 15 percent. And even small reductions will allow some people with hypertension to reduce their drug dosage or go off drugs entirely. Further, the blood-pressure drops in many people will be considerably greater than average. For people who manage to make the full array of changes, the declines might combine to yield dramatic improvements. And re-

search shows that practicing healthful habits can make people with hypertension feel healthier, too.

It's worth noting that most of those lifestyle changes are the same as or similar to the ones already recommended for protecting overall health.

Such steps reduce not only

blood pressure but also the risk of major diseases—including arthritis, cancer, coronary disease, diabetes, osteoporosis, stroke, and probably others as well.

Summing up

All people who have hypertension should try to take all of the following steps, whether or not they're also on antihypertensive drugs:

- Eat a diet that's high in fruits, vegetables, and dairy products, low in salt and fat.
- Exercise regularly, but not too vigorously.
- Lose excess weight by consuming fewer calories and exercising longer or more often.
- Limit your intake of alcohol and nonsteroidal anti-inflammatory drugs (NSAIDs).
- Stop smoking.
- Try to reduce stress, perhaps with cognitive-behavioral therapy.

For guidelines on whether you need medication, see the flowchart on page 7. For information on the various drug options, see our October 1996 issue. ■

For more information

- National Heart, Lung, and Blood Institute. For information on the DASH diet, write to the NHLBI at P.O. Box 30105, Bethesda, Md. 20824-0105. For information on other ways to treat or prevent hypertension, write to that address or access this web site: www.nhlbi.nih.gov/nhlbi/nhlbi.htm
- Harvard's DASH diet web site: dash.bwh.harvard.edu



Drugs

Herb watch

St. John's wort: Herbal Prozac?

Last year, the TV show "20/20" called St. John's wort (*hypericum perforatum*), a "startling medical breakthrough" in treating depression. A best-selling book, "Hypericum & Depression," raved about the herb. Such publicity has made St. John's wort so popular that manufacturers are having trouble finding enough plants to make the supplements.

A number of studies have suggested that St. John's wort may indeed help fight depression. Most of that evidence comes from Germany, where doctors often prescribe the herb. The British Medical Journal recently published the combined results of 23 small clinical trials of this remedy, involving some 1,800 volunteers with mild-to-moderate depression. The analysis indicated that St. John's wort is more effective than a placebo, and suggested that it might be as effective as standard antidepressant drugs for such depression. The study also found that the herb caused far fewer side effects than standard drugs did. Such findings have prompted the National Institutes of Health to launch a three-year multicenter trial of St. John's wort for depression.

The studies in the British analysis were too small or loosely designed to prove a benefit. And the U.S. FDA has received some reports of possible adverse reactions, ranging from dizziness to liver failure. However, the herb does appear to be generally safe and probably effective in the short run for people with relatively mild depression; no one knows yet about the long run.

If you decide to try St. John's wort, follow these guidelines:

- See a doctor first. A physician can rule out physical causes of depression, explain the other treatment options, and, if you're severely depressed, prescribe a standard antidepressant. Your doctor can also help monitor your progress on St. John's wort.

- If you're already taking a standard antidepressant, don't start taking the herb, reduce the antidepressant dosage, or discontinue the medication without your doctor's OK.

- Avoid products labeled less than 0.3 percent hypericin, which is the main active ingredient in *hypericum*, the herb itself. While no one knows the optimal dosage of the herb, most trials, including the NIH study now getting started, have used 300 milligrams of *hypericum* three times a day. (But since "dietary supplements" are largely unregulated, there's no guarantee that a product actually contains the indicated amount.)

- Give the herb at least two weeks to start working.

- Avoid excessive sun exposure, since St. John's wort may increase sensitivity to sunlight, especially in fair-skinned people.

- Children and pregnant or nursing women should avoid St. John's wort.

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Rough Draft

**YOU HAVE THE
POWER**

USE IT!

**THE REVOLUTION
OF EMPOWERMENT**

**JUSTIN DART
FRED PELKA, EDITOR**

CONFIDENTIAL

Rough Draft

"In order to win, we must galvanize our grass roots army to create a nation of barrier busters."

Patrisha Wright

"We have three top priorities: advocacy, advocacy, advocacy."

Ed Roberts

"Power concedes nothing without a demand"

Frederick Douglas

INTRODUCTION

Humanity clearly has the resources to live a golden age of science and democracy in which every person achieves a quality of life that is magnificent beyond the imagination of 19th century utopians. But humans remain stubbornly addicted to primitive perceptions and practices that close the gate to the Promised Land.

We are members of the civil and disability rights movements. We believe that people with disabilities and people without disabilities will never fully achieve any of their legitimate goals until there is a revolution to create a culture that systematically empowers every single individual to live his or her full potential for self-determination, productivity and quality of life. That revolution is possible if you, if we together, have the courage to act.

You have the power. You have the right, you have the responsibility to revolutionize your life and the lives of others for the better. There is no need to wait for any title or permission. You can be a revolution of one today. But you will not be alone. You will be joining the greatest army, the greatest family in the world - increasing thousands of the world's most beautiful people working in loving solidarity on history's most important project.

We have recorded several decades of pioneering progress in developing specific initiatives that widen the scope of human possibility. Our experience has proven absolutely that people with almost any physical, mental or social disability - when provided with the individualized tools of empowerment - can not only equal, but greatly exceed the norms of current mainstream society.

This booklet is a beginning attempt to distill that experience - to communicate a concept and an agenda for a revolution that will empower all people - people with and without disabilities, people who are poor, people who are rich - to live far better than they do now.

"Human progress is neither automatic nor inevitable. Even a superficial look at history reveals that no social advance rolls in on the wheels of inevitability. Every step toward the goal of justice requires sacrifice, suffering, and struggle, the tireless exertions of dedicated individuals."

Martin Luther King

We are extremely grateful to many great leaders of the civil and disability rights movements who have in one way or another contributed to this draft.

They include:

When we mention these distinguished individuals, we don't mean to imply that they necessarily endorse every word of this document. We do, however, wish to acknowledge their guidance and leadership.

"We are indeed on the edge of a great period of revolution. But it would be a great pity if our zeal were too easily assuaged by partial victories. We do well to recall that most revolutions have been lost precisely because they did not go far enough."

Jerome Bruner

HISTORIC CROSSROADS – DREAM OR DRIFT?

The disability rights movement, indeed humanity itself, stands at an historic crossroads.

Thanks to the pioneers of science and of equal-opportunity, free-enterprise democracy, thanks to you, humanity has created cultures that achieve standards of living and social justice beyond the wildest dreams of our ancestors of only a few centuries ago. America is a dramatic example.

Clearly we have the potential to eliminate poverty, discrimination and violence, to enable every person to live the human dream.

Will we do it, or will we, like great cultures past, relax in the status quo, and drift down the road of self-indulgence, special interest and disunity to the land of might have been?

“Injustice anywhere is a threat to justice everywhere.”

Martin Luther King, Jr.

THE PROBLEM – OPPRESSION IN THE MIDST OF PROSPERITY

The job of science and democracy is far from finished. In spite of humanity's astounding ability to create conspicuous affluence, hundreds of millions *still* live short desperate lives in situations of crushing oppression. Poverty and discrimination exist not only in developing nations, but in wealthy ones as well.

Moreover, the situation is getting worse. Three decades ago, the richest fifth of humanity had thirty times as much income as the poorest fifth. Today it has sixty-one times as much. Even in super-rich America, increasing millions of people are only marginal participants in the good life - or are left out completely. No person anywhere, rich or poor, is living as well as they could.

Throughout history, people with disabilities have always been the poorest of the poor, the most oppressed of the oppressed. Today sixty-seven percent of potentially employable Americans with disabilities are jobless. Millions live in poverty. Millions can't get health insurance at any price, unless they go on welfare. Millions are segregated in ghettos and backrooms, or are imprisoned in institutions. Hundreds of thousands are homeless.

Looking around the world, there are only a handful of countries that have mandated anything approaching full equality for people with disabilities, and there is no country on earth where full equality is a reality of daily life. In some countries, people with disabilities are not even allowed to vote, much less raise a family, go to school, or hold a job.

In many countries, people with disabilities are still beggars left to starve by the roadside. There are nations where 20 percent of children with disabilities do not survive beyond the age of 20, where 90 percent of children with intellectual impairments do not live to be six.

The first systematic mass murders committed by the German Nazis were of people with disabilities. Hundreds of thousands of disabled people were given lethal injections, forced into gas chambers, starved, or otherwise murdered.

"This is essentially a people's contest. On the side of the Union, it is a struggle for maintaining in the world that form, and substance of government, whose leading object is, to elevate the condition of men -- to lift artificial weights from their shoulders -- to clear the paths of laudable pursuit for all -- to afford all, an unfettered start, and a fair chance in the race of life."

President Abraham Lincoln
Message to Congress

Today, the killing continues. There are countries where the murder of babies with disabilities is still routine. In the United States of America there are increasing numbers of people who say that we who have disabilities are better off dead.

How many millions of people with disabilities around the world die every year from violence, or from lack of the basic necessities of life? Two million? Four million? Ten million?

Nobody knows. Dead whales they count. Dead spotted owls and butterflies they count. Nobody counts the deaths of people with disabilities. This is a contemporary Holocaust, an ongoing crime against humanity, which the international human rights community has barely acknowledged.

We must end this oppression and all oppression everywhere, not only for the sake of people with disabilities, but for all humanity. Because humanity is one. Oppression of anyone is oppression of everyone.

"As times change, so government must change. We need a new government for a new century -- humble enough not to try to solve all our problems for us, but strong enough to give us the tools to solve our problems for ourselves; a government that is smaller, lives within its means, and does more with less. Yet where it can stand up for our values and interests in the world, and where it can give Americans the power to make a real difference in their everyday lives, government should do more, not less. The preeminent mission of our new government is to give all Americans an opportunity -- not a guarantee, but a real opportunity -- to build better lives. "

Inaugural Address of President Bill Clinton
January 20, 1997

THE SOLUTION: A REVOLUTION OF EMPOWERMENT

Science and free-enterprise democracy give us the potential to eliminate poverty, discrimination and violence, to enable every person to live the human dream. But a devastating residue of primitive perceptions and practices prevent people from living that magnificent potential.

It is becoming increasingly apparent that humanity's old approaches to culture - even the best of them - have reached their useful limits. People cry out for a new vision of government and society - a vision that will identify the problem and harness our fantastic resources to enable all to live the good life that is clearly possible.

We have that vision.

The solution: A revolution that confronts and eliminates obsolete conceptions and systems. A revolution that focuses the full power of science and democracy on the systematic individualized empowerment of every person to live his or her full personal potential.

I propose that we of the civil rights and disability communities - and all who love justice - unite to lead a revolution of empowerment. We have unique knowledge and experience to offer.

You have been the great pioneers of empowerment; Labor right, civil rights, women's rights, voting rights, affirmative action, rehabilitation, 504, independent living, IDEA, supported employment, People First, ADA, PAS, CASA and much more. These are great initiatives - but they are only beginning steps toward the Promised Land. None of them even comes close to effectively meeting the needs of all the people they were designed serve. At best they are beacon lights of progress and hope in a dark sea of primitive values, attitudes, and systems, of residual authoritarian paternalism, of escapist self-indulgence. There is widespread confusion about the purpose of life and society, about the responsibility of individuals and the governments they create.

"If we believe that ADA is the power and we are the recipients of its strength, rather than we are the power and ADA is a tool for us to use, I fear we may still have a long way to go."

Bob Kafka

People with disabilities - people without disabilities - will never fully achieve any of their legitimate goals until the revolution of empowerment becomes the clearly focused first priority of individuals and society.

"The paramount goal of the United States was set long ago. It is to guard the rights of the individual, to ensure his development, and to enlarge his opportunity ... Our enduring aim is to build a nation and help build a world in which every human being shall be free to develop his capacities to the fullest. We must rededicate ourselves to this principle and thereby strengthen its appeal to a world in political, social and economic and technological revolution."

Canham, Conant, Darden, Greenwalt, Gruenther,
Hand, Kerr, Killian, Meany, Pace and Wriston
The Commission on Goals for Americans appointed
by President Dwight Eisenhower

EMPOWERMENT – WHAT IS IT?

What precisely is empowerment?

Empowerment is not empty rhetoric. There is a distinct and vital difference between, on the one hand, a society or government that empowers people, and on the other hand a society that either provides for and regulates them 'for their own good,' or devil-take-the-hindmost free market capitalism that allows people to amass money and power at the expense of others.

Empowerment is when we understand that the explosive success of modern democracies has never resulted from an unbridled free market, never from government by a paternalistic elite. Success has come when government, the private sector, religion, labor and citizens combined to empower the individual.

Empowerment is when we say no to the primitive illusion that society, government, the free market, the public media are some sort of paternalistic supergods that can give us truth, equality, and prosperity.

Empowerment is when we understand that society is nothing more than what we as individuals think and do every day. We are society. Only when we govern ourselves is there good government. Only when we produce is there full production.

Empowerment is when we understand that government for an age of science and democracy cannot provide rigid packaged solutions; it must instead provide a framework of principles and goals through which the trial and error of the scientific method and the democratic process can flow. It must enable all individuals to make the decisions, indeed to make the so-called mistakes, which are essential to the success of science and democracy.

Empowerment means choices.

*“Inclusion not exclusion. Independence not dependence.
Empowerment not paternalism and charity.”*

Senator Tom Harkin
and Bobby Silverstein

Empowerment is when we understand that productivity must be defined not only in terms of raw monetary balances, but finally in terms of quality of life produced.

Producing a billion dollars worth of cigarettes or land mines is not the same as producing a billion dollars worth of health care.

Empowerment means your productivity, your prosperity, your leadership - the quality of life of the child with mental retardation - is just as important as the productivity, leadership and the quality of life of the President of the United States.

The bottom line:

Empowerment is when we understand that we - each one of us - have the absolute power, and therefore the absolute responsibility, to change our lives - and society - today. Without permission from any leader, any government, any church - anyone. Because we really are society. When we change, society changes, instantly.

Empowerment is when we as individuals use our full power to establish lives of quality for ourselves and all. It happens in no other way.

These are some of the foundational concepts of a culture that empowers. ***Empowerment is a new central focus for social democracy. Government for the people, yes. But especially government of the people and by the people.*** This is a new vision of free enterprise - free enterprise that systematically empowers all to participate in its process, in its fruits. No more trickle down. No more paternalistic welfare. Aggressive, systematic individualized empowerment of all by all.

"I agree with you that this nation is founded on the principle that each human life is sacred and inviolable. People with disabilities have an absolute right and responsibility to participate fully and equally in society and to maximize their quality of life potential in manners of their own choosing."

President Ronald Reagan
Letter to the National Council on Disability
January, 1984

THE VALUES OF EMPOWERMENT

Empowerment requires a revolution in the values we actually live. We must stop pushing each other down in a self-destructive effort to achieve primitive symbols of power and prestige, and start lifting ourselves and each other to live well. Life is not a game that requires losers. People have been preaching about this for more than 2000 years, but we have been betrayed by our addictions to obsolete values, and by our dependence on paternalistic authority. We have been betrayed by our leaders who say, "Believe in me, give me your vote, give me your power, and I will give you the good life." That is not empowerment. That approach can never result in the good life for all.

These truths are self-evident:

Truth: All human beings have an inalienable right, an inalienable responsibility to live. Each human life, the quality of each human life, is sacred and inviolable.

Truth: All human beings have an inalienable right and an inalienable responsibility to govern their own lives, to govern society, to invest all of their abilities and resources in producing lives of quality not only for themselves and their families, but for all.

Truth: The purpose - the first and fundamental priority - of society and its governments is not to govern people and to provide the good life for them, but to empower them - all of them - to govern themselves and to provide the good life for themselves and their fellow humans.

Truth: Empowerment to govern oneself does not imply freedom from the great universal values of social responsibility. On the contrary, empowerment mandates absolute individual and collective responsibility for those self-evident values that support the preservation and quality of human life - and on which all great religions and cultures agree.

"This is life.... This is no make-believe world where you can go jumping into everything and it will be OK. You have to live up to your responsibilities and answer for your errors."

Herschel Walker

"It is the right and the responsibility of disabled people (of all oppressed people) to redefine themselves (their identities and their values) as opposed to accepting the definitions imposed by our oppressors."

Bruce Curtis

Truth: Human beings are by nature interdependent. Individual, family, society and universe form a continuum of interdependence. You cannot be responsible for your own family without being responsible for the society and the natural environment in which they live.

Freedom of choice does not validate purchasing a luxury car and a palatial home with funds that are needed for the health care and education of future generations.

Empowerment is when the good life for all is the first, not the second or last - value of every person and organization.

*"We must replace the welfare state with an opportunity society.
Every American is entitled to a life filled with opportunity."*

Representative Newt Gingrich
Speaker, U. S. House of Representatives
1995

A DRAFT AGENDA FOR EMPOWERMENT

What are the specific agenda items, the specific long-range goals of the revolution of empowerment? These goals will always be in a state of dynamic development. We submit this draft platform as a beginning for discussion.

Government by All

Government must stop dictating solutions, and provide the specific support that will empower each individual to govern self and society. This will require universal registration, voting and direct participation in government through telecommunication, campaign reform, intensive education and much, much more.

Human Rights for All

Government at all levels must mandate and enforce the inalienable right of every person - with or without a disability, sick or well, young or old, male or female - to live, to be protected from assaults on body and dignity, and to live free. No murder or mutilation of anyone. No assisted death. No forced institutionalization or isolation of any kind.

Equal Opportunity for All

Government must mandate and enforce the inalienable right of all people to have full, equal and effective opportunity to participate in every aspect of culture in manners of their own choosing.

In America we must protect, implement, and strengthen the ADA and all civil rights laws. Gays and lesbians and others must receive full protection. We must increase investments in civil rights enforcement, and especially in education to inform citizens, businesses and local governments of their rights and obligations. We must increase investments in legal services that give ordinary people real access to justice.

“Men who are good by reason -- i.e., men who, under the guidance of reason, seek what is useful to them -- desire nothing for themselves which they do not also desire for the rest of mankind.”

Benedict (Baruch) Spinoza

Choices for All

Government must guarantee to each citizen full access to resources of the culture. This can be done through a one-stop computer linked continuum of integrated empowerment services available to each person from birth to death. Each person must be enabled to create and continually develop a package of individualized public and private services to empower him or her to govern self and society, to be productive, and to live a life of maximum quality.

Every child and every adult must be provided a computer adapted to meet his or her individual needs. Wealthy people can pick up their telephones and access expert counselors who enable them to choose from among thousands of investment opportunities worldwide, and to make transactions in seconds. Human services can be provided in the same way.

Health Care for All

Government must guarantee that all people receive comprehensive, quality, lifetime health care that empowers them to choose their doctors and treatments. All necessary health services must be covered, with no financial limits, with no forced treatment. Rationing health care and vital health related services are not options of a civilized society.

For the short term we must defend and strengthen Federal guarantees of Medicaid and Medicare, and other empowering health care programs at the national, state and local levels.

Freedom for All

Government must guarantee lifetime consumer controlled home and community based services that empower all people to live and to participate in their communities in manners of their own choosing. Let no American ever again suffer enforced isolation in an institution, a nursing home, a back room or any other place.

In the short term we must support the strongest possible version of the CASA bill, and all other initiatives that begin to develop comprehensive long-term consumer controlled empowerment services.

"The dignity of risk is what the movement for independent living is all about. Without the possibility of failure, the disabled person is said to lack true independence and the mark of one's humanity—the right to choose for good and evil."

Gerben DeJong

Education for All

Government must guarantee birth to death education, including higher education, which enables all individuals to choose from among the entire spectrum of public and private educational and information resources. Universal, lifetime education is absolutely necessary in an age of exploding change and complexity.

Much of this education can occur through telecommunications which empower each individual to construct customized educational packages. For example, a person might simultaneously take courses from Harvard, Tokyo University, IBM, and his or her local community college. He or she could access information from the library of Congress and NASA, participate in internships with various public and private organizations, and interact with individuals around the world. This process must be facilitated through expert one-on-one counseling with individuals empowered to choose their own qualified counselors.

We must protect, strengthen, and expand the IDEA. All people with disabilities must receive free and appropriate education in the least restrictive environment - and with all existing due process protections in place.

Employment for All

Government must guarantee birth to death services that empower all individuals to achieve their full potential for fulltime or part-time employment.

All individuals who can work must be enabled to choose from among an integrated continuum of services - educational, recreational, cultural, rehabilitation, independent living, supported employment, counseling, social security, and welfare - that empower them to have decent jobs with decent pay and decent standards of living.

We must protect, strengthen, and refine the Rehabilitation Act - creating an expanded form that streamlines process, that maintains the integrity of independence oriented services, that makes services available to all who need them, that mandates full consumer choice and control. We must eliminate

"Generations of exclusion and oppression of people with disabilities have been declared ended by the ADA. We are recognized as equal members of the human family. But like other oppressed groups in history it will take us time to overcome the shame, the fear, the pity, the paternalism and prejudice that we have owned for eons. Universal access will not happen overnight. The ADA is a sword and shield that we must wield to empower ourselves."

William G. Stothers
Managing Editor
Mainstream Magazine

employment disincentives from the Social Security and related health care systems.

Dignity for All

Government must guarantee lives of dignity for all who can't work, or who are working, but can't achieve decent standards of living. We must reconstruct Social Security and welfare to create programs that encourage all people to be productive and at the same time guarantee freedom from want. We must give the first priority to the interests of children, because they will of course determine the future of humanity. Cuts in SSI payments to children with disabilities must be restored.

Housing for All

Government must guarantee all individuals affordable, accessible and quality housing. All new housing must meet the standards of universal design. All rooms in all homes must be accessible to all members and friends of the family, no matter what their age, disability or health. No one should ever be forced by disability to move, remodel, or enter a nursing home. Grandma can visit.

Communications and Technology for All

Government must guarantee all individuals practical, affordable access to all communication systems and other technology. We have the technology to turn every living room, hotel room and office, into a workplace, a university, a theater, a shopping center, a government office, a voting place, and a place of intimate communication with family and friends around the world.

Transportation for All

Government must guarantee public and private transportation that is affordable and accessible to all. There should be greatly increased investment in efficient accessible public transportation. No one should be forced to drive an automobile in order to participate in the mainstream society.

“Passing ADA was incredibly historic. Now every day we must fight to make sure that the words in the law, the words on the White House lawn, the words in the House and the words in the Senate become reality for 43 million Americans with disabilities and millions more around the world who are looking to American leadership for the rights of the disabled.”

Representative Steny Hoyer

Communities for All

Government must provide leadership to develop new communities that are accessible as a whole. There must be no segregation of any kind. Government and the private sector must cooperate to create new experimental communities.

- Communities where all public places and services will be completely accessible and convenient to, and completely affordable by all people. Everyone participates. Everyone contributes.
- Communities, without gridlock and ghettos, where you can commute to job, supermarket, house of worship or medical services in five or twenty minutes on foot or wheels, in protected malls, and by underground public transport.
- Communities where green land replaces garbage-covered concrete.

We built the shopping center. It's time to build the living center.

A World for All

Government must coordinate with the private sector and individuals to create a foreign policy that supports the empowerment of people in every nation. We must advocate, we must demand that the United Nations does the same.

Responsibility for All

Government must coordinate with the private sector and individuals to reconstruct tax-codes so that all will pay their fair share. At the same time we must substantially revise the budgets of government at all levels, cutting the fat, the paternalistic bureaucracy, and the special interest subsidies and greatly expanding investment in empowerment services. We have a responsibility to our children to eliminate deficits and national debt.

"What an opportunity we have! Independent living was once a dream, and now it is becoming a reality. A better future for hundreds of thousands of people with disabilities is within our grasp ... Our greatest handicaps are outdated social attitudes, lack of opportunities and physically inaccessible environments. Together we can change all that and can create the new future. I urge you to take the challenge; ..."

Ed Roberts
Father of Independent Living

QUESTIONS - STEREOTYPES

Stereotype: Full equality for people with disabilities is inappropriate, people with disabilities are a small minority of tragic victims that can be taken care of through minimal welfare and charity.

Stereotype: People with severe disabilities are better off in institutions, nursing homes and prisons. Some people with disabilities are better off dead.

Truth: People with disabilities are not tragic; they are not a minority. Science and democracy have created a new human. Since 1800 we have more than doubled the average human life span. With modern medical treatment the majority of humans - in America seven out of ten - will triumph over death to live with a disability at some point in their lives. Every single family in the world will experience the triumph of survival with disability. Disability is a normal characteristic of the new human. People with disabilities are not a tragic minority. They are a magnificent, triumphant majority.

A society that does not meet the needs of people with disabilities does not meet the needs of anyone.

Truth: Science gives all new humans, with and without disabilities, a new potential to be a hundred times more productive, to live immeasurably better than our strongest, smartest, richest ancestors of only 200 years ago. But we are allowing old attitudes to limit this magnificent potential.

Stereotype: Isn't empowerment really just another attempt to justify massive paternalistic government regulation?

Truth: On the contrary, empowerment is liberation from paternalism. Empowerment of all individuals means full participation and leadership by business, labor, communities, community groups, religions, families, and most of all individuals. A leaner, less intrusive government that is focused on empowerment will actually be stronger and more effective in producing real social change. It will empower private sector organizations, families and

"A society good for disabled people is a better society for all. All of us gathered here today know that this is true. Let us use our insight to convince others!"

Bengt Lindavist
The United Nations

"And when you add together federal, state, local and private funds, it costs almost \$200 billion annually to support Americans with disabilities, in effect, to keep them dependent. Well, when given the opportunity to be independent, they will move proudly into the economic mainstream of American life, and that's what this legislation is all about ... I now lift my pen to sign this Americans with Disabilities Act and say, let the shameful wall of exclusion finally come tumbling down."

President George Bush
July, 1990

individuals to solve their own problems as with the GI bill, the FHA and federal support for independent living.

Stereotype: Full equality for people with disabilities costs too much.

Truth: Society, government can't afford *NOT* to empower all its people. The paternalistic status quo is creating deficits and poverty.

Poor countries are poor because their people are not empowered. Rich countries have huge welfare costs because they have not empowered all their people. Japan has relatively few natural resources, but it is one of the richest countries in the world – because it has made major investments in the economic potential of its individual citizens.

Empowerment will bring a positive explosion in the economy and quality of life that will dwarf the industrial revolution. The nations that do it first will assume economic and moral leadership of the world.

Stereotype: The revolution of empowerment is politically impossible. Be grateful for our gains, defend, fine-tune the status quo or even, “Go back to the good old days.”

Truth: Retreat and acquiescence in the status quo would betray all present and future humans. Humanity's task now is to go aggressively forward, to focus the full force of science and free enterprise on creating a culture that will systematically empower every person.

Stereotype: Working for a revolution of empowerment means neglecting current national and local issues.

Truth: We must work more, not less, on specific current issues, but always framing them in the vision of an empowerment society. The local legislation, voting rights, housing, personal assistance services you are promoting, the funding you are seeking, will never be fully achieved until you can justify them as part of a plan to provide the good life for all.

"When we rule ourselves, we have the responsibilities of sovereigns, not of subjects."

President Theodore Roosevelt

"... man being condemned to be free carries the weight of the whole world on his shoulders; he is responsible for the world and for himself as a way of being ... the peculiar character of human morality is that it is without excuse."

Jean Paul Sartre

THE BIG QUESTION

Can we communicate our truth? Can we win the revolution of empowerment?

History and the evening news say that we're probably not going to make it to the land of our dream.

We *CAN* make it. The empowerment culture is possible. We can create a revolution of empowerment – a golden age of science and democracy for all. We have the money, the talent, the technology. But do we have the will?

How can we possibly overcome the ancient attitudes, the powerful lobbies for the status quo and retreat?

Who will complete the revolution of empowerment? Who will make the dream live?

Look in the mirror. You are responsible. We are responsible.

Each one of us is responsible to every person, to every family in the world, present and future.

We of the disability community have unique responsibility because we have several decades experience creating and refining successful empowerment programs, such as rehabilitation, IDEA, independent living, supported employment, ADA and many others.

But some of you may say, "Well, I have no money, no title. I'm not Joshua Malinga, Judy Heumann, or Marca Bristo. I'm not Nelson Mandela or Bill Clinton. I'm not a leader. What can I do?"

You can do everything. When you change yourself, you have changed the society.

But is it worth the struggle – the hard work? Is it worth the sacrifices and risks?

“Let us suppose that certain individuals resolve that they will consistently oppose to power the force of example; to authority exhortation; to insult, friendly reasoning; to trickery, simple honor. Let us suppose they refuse all the advantages of present day society and accept only the duties and obligations which bind them to other men. Let us suppose they devote themselves to orienting education, the press and public opinion towards the principles outlined here ...

Then I say that such men would be acting not as Utopians but as honest realists. They would be preparing for the future and at the same time knocking down a few of the walls which imprison us today. If realism be the art of taking into account both the present and the future, of gaining the most while sacrificing the least, then who can fail to see the positively dazzling realism of such behavior? ...”

Albert Camus

There will be hard work. There will be sacrifice. There will be the kind of personal risks that great pioneers in human rights have always taken. But you will be the winner.

Even if no other person follows you, you will have made your own life, your own family, your own community, humanity as a whole more productive and more loving. You will have improved the quality of life of yourself and all. You will experience that deep happiness and pride that comes only with fulfilling the most profound responsibility of human being.

But you will not be alone. There are increasing thousands of us - a great army, an enormous family of brothers and sisters in justice.

You know the secret. You are the society.

You have the power, and therefore the responsibility to change the world simply by changing your own personal action. Act!

“Emphasize the continual creation of new leadership; keep dividing organizations into more groups and subgroups in order to force more members into leadership roles. Encourage members to express and promote their own ideas in their own ways and through their own actions—speaking, writing, singing, praying, signing, whatever.”

Bob Cooper
Past President
Rhode Island Handicapped
Action Committee

ACTION – 10 THINGS YOU CAN DO TO CHANGE THE WORLD

1. Act now, don't wait. You don't need a special permission, a lot of money or a title to change the world. You don't have to wait for anyone or anything. You can become a revolution of one - today - in your own living room, in your own community.
2. Speak constantly about the revolution of empowerment. Communicate your message on every possible occasion – to your family, your friends, your neighbors, your colleagues at the work place, and to the person sitting next to you on the bus.

Become a public person. Communicate the revolution of empowerment in simple terms over and over again – by letter, by calls, in person - to members of government, business people, newspapers, television, radio talk shows. Attend every possible meeting with your homemade signs.

3. Become an active member of the local and national disability rights organizations of your choice. There are many honorable and necessary roles to play – from stuffing envelopes and making calls to organizing meetings and participating in demonstrations and civil disobedience. If you can possibly afford it, make cash contributions. No matter how few your dollars, they will make a difference because, unlike government or foundation grants and contracts, they will provide no-strings money that can be spent on aggressive advocacy.
4. Every time you advocate anything – ADA, IDEA, Independent Living. Supported Employment, access or your own personal rights - connect your issue to the revolution that will empower all to achieve their full potential to participate in all aspects of life.

We must do this in order to communicate the truth that our agenda is not a special interest agenda, that without it no person, no family will ever achieve their potential to live the dream, and that the revolution of empowerment is the first priority of human society.

"... No doubt about it, ADA can be a win/win for everyone, if we are willing to work together and apply common sense."

Senator Bob Dole
July, 1995

"The ADA sends a simple powerful message to the world. Disability is a natural part of the human experience that in no way diminishes an individual's fundamental right to be a full participant in all aspects of society. Across Iowa and around the country, I have seen how the ADA has literally transformed people's lives. Individuals with disabilities have told me they are "empowered" by the ADA. Has the ADA resulted in full equality in five short years? Have all the physical, transportation and attitudinal barriers facing people with disabilities come down? Of course not. We all know that couldn't happen over night. To me, the most important point is we have started on a journey to the promised land of full equality, dignity and respect. The ADA is a map to guide us to that promised land. The ADA is fair and balanced and must be maintained. The world is watching."

Senator Tom Harkin
July, 1995

We must communicate to all that the revolution of empowerment will benefit them personally.

5. Become a politician for empowerment. Vote. Participate in the party of your choice. Volunteer to work in the campaigns of candidates who support empowerment. Attend rallies with your signs and flyers. Contribute money to good candidates. A contribution of \$5, \$25, \$100 puts you on a different list. Run for office.
6. Recruit as many people as possible to be leaders for empowerment. We have the best movement, with the most loving, principled people ever, people like you. But there aren't enough of us. We must empower thousands of new leaders.

One wheelchair user in Tennessee could recruit only her nine-year old son. He became a spokesperson for the disability rights movement on local and national television.

7. Pursue a politics of solidarity with all who love justice. We of the disability and human rights movements may differ in words and methods. But we all agree on the final goals: Liberty and justice for all, empowerment for all, the good life for all. United we stand. Divided we fall.

There is no conflict between individual rights and unity. Human beings are inherently individualistic. At the same time we are inherently interdependent. The great strength of America has been that we are a nation of individualists who at moments of historic decision have stood in solidarity for the great universal values of humanity.

Become a card-carrying member of as many empowerment organizations as possible. If you can't afford the dues find other ways to communicate your solidarity. Become familiar with their issues and express your public support.

*He drew a circle that left me out
– Heretic, rebel, a thing to flout,
but love and I have the wit to win:
We drew a circle that took him in.*

Edwin Markham

8. Reach out to unite with our oppressed colleagues in every nation. Join and support Disabled Peoples International and other organizations for people with blindness, deafness, psychiatric disabilities, and developmental disabilities. Contact and join disability rights organizations in individual nations. Advocate with the United Nations.
9. Pursue a politics of love. Love has an almost magical power. Attack stereotypes. Attack bad ideas and bad policies. Love individual people, no matter what their ideas. Every person responds to love. Love has powered all great revolutionary leaders, including Jesus, Mahatma Gandhi, Martin Luther King, Jr.

Every time you communicate our message of empowerment give sincere loving recognition to the person with whom you are communicating. Every one has good qualities.

Repeat the same loving, positive message of empowerment over, and over so that when people see you coming they will think, "Here comes that great empowerment person, she appreciates me."

10. Pursue a politics of truth. We have the truth. We don't need to exaggerate or to be evasive. Truth is a great power. Use it.

"Perfection of means and confusion of goals seem--in my opinion--to characterize our age. If we desire sincerely and passionately the safety, the welfare and the free development of the talents of all men, we shall not be in want of the means to approach such a state. Even if only a small part of mankind strives for such goals, their superiority will prove itself in the long run."

Albert Einstein

SUMMARY

Colleagues, we have solutions. We have great goals. But we are never going to fully achieve any of them until we communicate the truth about empowerment to the world.

The world is watching our movement, the world is watching democracy. The world will follow what we do. Failure is unthinkable.

No soldier ever died in a better cause.

We've got to get off of the defense and onto the offense.

Get into empowerment, get into politics, as if your life depended on it. It does, and so do the lives of all humans in the 21st century.

Colleagues, you have proved that free people can prevail over paternalism and prejudice. You are proving that the human dream can live. You have made miracles in millions of lives.

Let us embrace and lift each other. Let us reject hostility, self-indulgence and retreat. Let us go forward together in the great tradition of Jefferson, Lincoln, Gandhi, Martin Luther King, Nelson Mandela, Ed Roberts, Bengt Lindqvist, Henry Enns, Wade Blank and Elizabeth Boggs. Let us greet intimidation with courage, hate with love, demagoguery with simple truth. Let us overwhelm fear and fallacy with our vision of a society that empowers all.

Let us unite to shout together, each in our own words, each in our own actions, "People of the world, you have power! Join us in the revolution of empowerment. Join us in building the society of our dreams."

*The Woods are lovely, dark and deep.
But I have promises to keep,
and miles to go before I sleep.*

Robert Frost

F. Marc LaForce, M.D.
Director

Jay M. Wussow, M.P.H.
Deputy Director

May 15, 1998

Lex Frieden
Senior Vice President
The Institute for Rehabilitation and Research
1333 Moursund Street
Houston, TX 77002

RE: Robert Wood Johnson Foundation grant ID#: 031313

Dear Mr. Frieden:

Lex

By now you should have received a letter from Janice Opalski, Director of Financial Monitoring of the Robert Wood Johnson Foundation (correspondence dated March 18, 1998). This correspondence indicated that as of April 1, 1998, the *Building Health Systems for People with Chronic Illnesses* (BHS) National Program Office (NPO) is responsible for approval of all budget revisions, extension requests and subcontracts. In addition, the BHS NPO will acknowledge the submission of financial and narrative grant reports.

We are writing today to ensure that you understand the implications of this additional National Program Office responsibility, to clarify the process for submitting any budget revision or extension requests, and to review the grantee reporting requirements. With this letter, I have enclosed the following materials:

- Summary of all grantee reporting requirements for the Robert Wood Johnson Foundation's *Building Health Systems* Program;
- Contact information for all BHS NPO staff, and relevant RWJF staff;
- Outline of process for submission of budget revision and/or budget extension requests;
- Schedule of report due dates for the above noted grant;
- A copy of the financial reporting form for the current budget period on the above noted grant;
- A copy of the Robert Wood Johnson Foundation's Grantee Reporting Instructions;
- The Robert Wood Johnson Foundation's Financial and Budget Guidelines.

As noted in the April 1, 1998 letter, RWJF has made this adjustment to the approval process in an effort to facilitate responsiveness to its grantees. As in the past, the *Building Health Systems* National Program Office should be the first point of contact for any questions about the administration of your grant award (payments, reporting requirements, programmatic issues, etc.).

Center for Health Care Strategies, Inc.

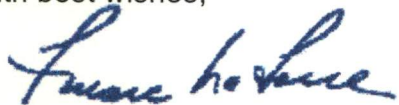
Affiliated with the Woodrow Wilson School of Public and International Affairs at Princeton University

The Robert Wood Johnson Foundation requires the submission of financial reports on a semi-annual basis (every six months) and an Annual Progress Report (every 12 months). In addition, the *Building Health Systems* National Program Office requires the submission of Quarterly Update Reports. A schedule for the submission of all required grant reports is enclosed with this letter. Also enclosed is a description of each report, as well as the guidelines for preparing all reports also is enclosed. Contact information for all relevant staff at the *Building Health Systems* National Program Office and the Robert Wood Johnson Foundation is provided as well.

The process for submitting a budget revision or extension request is outlined in an attached document. In summary, though, a budget revision or extension request should always begin with a conversation with the *Building Health Systems* National Program Office (either Jay Wussow, Deputy Director, or Sheila Weeks-Brown, Financial Officer). We will discuss with you the rationale for the proposed budget revision or extension and determine the necessary paperwork that should be submitted, including appropriate financial information and narrative information to explain the revision. The grantee will then submit a DRAFT of the proposed budget revision for comment and review by the *BHS* NPO. When the *BHS* NPO and the grantee have agreed upon a suitable version of the budget revision request, the grantee will formally submit a budget revision request, with copies sent to both the *BHS* NPO and to the RWJF Financial Monitoring Office. The *BHS* NPO will then process the formal submission. As noted in the March 18, 1998 correspondence from Janice Opalski at RWJF, the *BHS* NPO will be responsible for approval of budget revision requests, once a formal request has been submitted.

If you have any questions about your grant award, the information in this letter, or any of the enclosed materials, please feel free to contact Jay Wussow, *BHS* Deputy Director (phone: 609-279-0700, e-mail: jw@chcs.org) or Sheila Weeks-Brown, *BHS* Financial Officer (phone: 609-279-0700, e-mail: swb@chcs.org). We would be happy to discuss any programmatic, financial, or reporting issue concerning your project.

With best wishes,



F. Marc LaForce, M.D.
Program Director



Jay Wussow
Deputy Director

finmon1.doc
Enclosures

cc: Rosemary Gibson
Rona Smyth Henry
Sheila Weeks-Brown
Stephen Somers, Ph.D.

F. Marc LaForce, M.D.
Director

Jay M. Wussow, M.P.H.
Deputy Director

The Robert Wood Johnson Foundation and *Building Health Systems for People with Chronic Illnesses* Program

GRANTEE REPORTING REQUIREMENTS

There are three types of reports required by grantees of the Robert Wood Johnson Foundation's (RWJFs) *Building Health Systems for People with Chronic Illnesses* (BHS) Program: Semi-Annual Financial Reports, Annual Progress Reports, and Quarterly Update Reports. A Final Grant report also is required at the closure of a grant. In addition, site visits may be conducted on a periodic basis. Each report is described below

I. Semi-Annual Financial Reports (to be submitted every six months):

- Three (3) copies should be sent to the *Building Health Systems for People with Chronic Illnesses* National Program Office (NPO), Attention Sheila Weeks-Brown; and
- Three (3) copies should be sent to the Robert Wood Johnson Foundation, Attention: Rona Smyth Henry.

The Robert Wood Johnson Foundation utilizes a semi-annual financial reporting and payment schedule for grantees. All grantees are required to submit financial reports that document the grant-related expenses incurred during that six-month budget period. These reports should be submitted to both RWJF and to the *BHS* National Program Office every six months (or two times each budget year).

Semi-Annual Financial Reports are due 30 days after the end of a budget period (for example, if the last day of a budget period is March 31, then a financial report is due by April 30). Upon submission of a Semi-Annual Financial Report, a financial reporting form will be forwarded to the grantee to be used when submitting the next financial report. The financial reporting form indicates the approved budget for that budget period.

NOTE: The submission of semi-annual financial reports prompts the next payment of grant funds to a grantee. As such, payments will not be made until an accounting of the previous period's expenses has been submitted.

If you have any questions on financial reporting requirements, please contact Sheila Weeks-Brown, Financial Officer at the *Building Health Systems for People with Chronic Illnesses* National Program Office (phone: 609-279-0700, e-mail: swb@chcs.org).

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Grantee Reporting Requirements

II. Annual Progress Reports (to be submitted for each budget year)

- Three (3) copies should be sent the *Building Health Systems* NPO, Attention Jay Wussow; and
- Three (3) copies should be sent to the Robert Wood Johnson Foundation, Attention: Rona Smyth Henry.

The Robert Wood Johnson Foundation requires the submission of an Annual Progress Report for each budget year of a grant. Typically Annual Progress reports are submitted every 12 months. Annual Progress reports may be submitted to reflect shorter time periods, if a budget year is less than 12 months (i.e., the first 6 months of an 18-month grant may require the submission of an Annual Progress Report, if the budget was constructed in this manner). The format outlined in the Robert Wood Johnson Foundation's *Grantee Reporting Instructions* should be utilized for the submission of Annual Progress Reports.

Annual Progress Reports are due 30 days after the end of a budget year (for example, if the last day of a budget year is March 31, then an Annual Progress report will be due by April 30). Upon receipt of each Annual Progress Report, the *Building Health Systems* National Program Office *may* schedule a conference call with the Principal Investigator of the project. This call would be utilized to discuss the progress of the grant and to follow-up on any issues raised during the previous quarter.

If you have any questions about the submission or format for Annual Progress Reports, please contact Jay Wussow, Deputy Director of the *Building Health Systems for People with Chronic Illnesses* National Program Office (phone: 609-279-0700, e-mail: jw@chcs.org).

III. Quarterly Update Reports (Submit 3 per budget year):

- Three copies should be sent ONLY to the *Building Health Systems* NPO.

Each quarter, the *Building Health Systems* NPO should receive a brief summary of the activities, principal accomplishments, principal shortfalls and problems encountered by the project during the reporting period. This brief quarterly report may be written in an outline, or bullet-point format, but should be limited to no more than three (3) pages (the format for this quarterly update report is attached).

Please note that only three quarterly reports are required each year. The more lengthy and detailed Annual Progress Report will be utilized during the fourth quarter of a given budget year.

Upon receipt of each Quarterly Update Report, the *Building Health Systems* National Program Office *may* schedule a conference call with the Principal Investigator of the

Building Health Systems for People with Chronic Illnesses Program **Grantee Reporting Requirements**

project. This call would be utilized to discuss the progress of the grant and to follow-up on any issues raised during the previous quarter.

IV. Final Grant Report (to be submitted at the closure of a grant):

- Three (3) copies should be sent the *Building Health Systems* NPO, Attention Jay Wussow; and
- Three (3) copies should be sent to the Robert Wood Johnson Foundation, Attention: Rona Smyth Henry.

At the close of each grant, the Robert Wood Johnson Foundation requires each grantee to submit a Final Grant Report. The format outlined in the Robert Wood Johnson Foundation's *Grantee Reporting Instructions* should be utilized for the submission of Final Grant Reports.

NOTE: The final grant payment will not be made by the Robert Wood Johnson Foundation until both the final grant narrative report and the final financial report.

If you have any questions about the submission or format for the Final Grant Report, please contact Jay Wussow, Deputy Director of the *Building Health Systems for People with Chronic Illnesses* National Program Office (phone: 609-279-0700, e-mail: jw@chcs.org).

V. Site Visits:

The *Building Health Systems for People with Chronic Illnesses* Program conducts site visits to its grantees on a periodic basis during a grant and at the close of a grant. These site visits are conducted in order to receive an update on the status of the project, to discuss the project's principle accomplishments, and to discuss any shortfalls or barriers that may have occurred. The purpose of site visits is to ensure that the *Building Health Systems* National Program Office has a clear understanding of the project's progress and to help the site address any difficulties in implementing the project. The *BHS* National Program Office will contact a grantee when it would like to conduct a site visit, and work with the grantee to identify an appropriate date for the visit. The *BHS* NPO also will work with the grantee in developing the agenda for these visits. Members of a site visit team will always include staff from the *BHS* National Program Office, and may also include staff from the Robert Wood Johnson Foundation, members of the *BHS* National Advisory Committee, and/or other experts in the field.

Generally, the *BHS* Program conducts site visits approximately midway to completion of the project, and at the close of the grant. Additional visits may be conducted at the discretion of the *BHS* National Program Office and the Robert Wood Johnson Foundation. The *BHS* Program typically conducts an end-of-grant site visit after the submission of the project's final report (usually within three-months of the close of a grant).

F. Marc LaForce, M.D.
Director

Jay M. Wussow, M.P.H.
Deputy Director

QUARTERLY UPDATE REPORT FORMAT

Each quarter (every three months), the *Building Health Systems for People with Chronic Illnesses* National Program Office (NPO) should receive a **brief** summary of the activities, principal accomplishments, principal shortfalls and problems encountered by the project. Three copies should be sent ONLY to the *Building Health Systems* NPO, Attention: Jay Wussow.

Upon receipt of each Quarterly Update Report, the *Building Health Systems* National Program Office may schedule a conference call with the Principal Investigator of the project to discuss the progress of the grant and to follow-up on any issues raised during the previous quarter.

NOTE: Only *three* (3) quarterly reports are required each year. The more lengthy and detailed Annual Progress Report will be utilized during the fourth quarter of a given budget year.

REPORT FORMAT:

1. Limit your report to a length of three (3) pages. You may utilize an outline or bullet-point format.
2. Type the first page of the Quarterly Update Report on a sheet of your institution's or organization's letterhead stationery. Date the page, head it "QUARTERLY UPDATE REPORT Year (1, 2, 3, or 4), Quarter (1, 2, or 3)," and provide the following information:
 - the title of your project,
 - its RWJF grant identification number, and
 - the dates covered in the report.
3. Use the following as headings for the body of the Quarterly Update Report:
 - *Principal Objectives:*
List briefly the objectives that were to be accomplished during this quarter, as indicated by the project workplan;
 - *Principle Accomplishments:*
Outline the accomplishments of the project during the report period and describe how they relate to the principal objectives (objectives may be used as subheadings);
 - *Principle Shortfalls and/or Barriers:*
Outline the principal shortfalls of the project and the principal problems encountered during the report period. Outline how these shortfalls or problems were or are going to be addressed.
4. Outline what major factors affecting the project have changed during the reporting period, to the extent not previously covered.
5. The Principal Investigator for the project should sign each report. Provide the name and phone number of a contact person to schedule a follow-up conference call with the *Building Health Systems* National Program Office, if necessary.

Center for Health Care Strategies, Inc.

Affiliated with the Woodrow Wilson School of Public and International Affairs at Princeton University

F. Marc LaForce, M.D.
Director

Jay M. Wussow, M.P.H.
Deputy Director

Contact Information for Staff of The Robert Wood Johnson Foundation and The *Building Health Systems for People with Chronic Illnesses* Program

Building Health Systems for People with Chronic Illnesses Program

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E-MAIL: mlaforce@rghnet.edu

NATIONAL PROGRAM OFFICE:

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Center for Health Care Strategies, Inc.

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Director

Jay M. Wussow, M.P.H.
Deputy Director

The Robert Wood Johnson Foundation and *Building Health Systems for People with Chronic Illnesses* Program

Process for Submission of Grant Budget Revision Requests

The Robert Wood Johnson Foundation (RWJF) and the *Building Health Systems for People with Chronic Illnesses* (BHS) Program understand that changes may need to be made to the approved grant budget for a project. These changes may result from programmatic changes during the implementation of a grant, the need for additional line items, and/or changes in the timeframe for implementing specific workplan objectives. While the Foundation cannot change the dollar value of a grant once it has been awarded, grantees may propose revisions to their approved grant budget. Outlined below is the process for submitting a grant budget revision or a budget extension request to the Robert Wood Johnson Foundation's *Building Health Systems* Program. Please follow these guidelines when submitting a budget revision request.

1. When a grantee is considering the submission of a budget revision request, the first point of contact should ALWAYS be the *Building Health Systems* National Program Office. A telephone call to either Jay Wussow, Deputy Director, or Sheila Weeks-Brown, Financial Officer, should be made to discuss the rationale for submitting a budget revision request. Jay Wussow and Sheila Weeks-Brown may be reached at 609-279-0700.

The BHS National Program Office will discuss with you the programmatic issues that may necessitate a budget revision request, and advise you on the information that would be required to support a proposed budget revision.

2. A DRAFT budget revision request should be submitted to the BHS NPO for review and comment. The draft should indicate the specific changes that are being proposed to the grant budget, and a narrative should be provided that provides a rationale for the proposed budget revision.
3. The BHS NPO will review the draft to ensure that it is in accordance with The Robert Wood Johnson Foundation's financial guidelines and that the narrative provides a suitable rationale for the proposed budget revision. In addition, the proposed budget figures will be reviewed to ensure that they reflect the expenses incurred during prior budget periods. Additional drafts of the budget revision request may be needed if

Center for Health Care Strategies, Inc.

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additional information is needed or if changes should be made to reflect Foundation guidelines.

4. When the *BHS* NPO and the grantee agree upon a final draft of the budget revision request, the grantee will be asked to submit a formal budget revision request. The formal budget revision request should be submitted on the grantee organization's letterhead and should be signed by the principle investigator and/or the grantee organization's financial representative. Please submit three (3) copies to the *BHS* National Program Office. One (1) copy also should be forwarded to the Robert Wood Johnson Foundation's Financial Monitoring Office, Attention: Rona Smyth Henry, Senior Financial Officer (please see the attached contact list for addresses).
5. Upon receipt of a formal budget revision request, the *BHS* NPO will process the revision. Final processing will include a final review of the financial figures and programmatic rationale.

F. Marc LaForce, M.D.
Director

Jay M. Wussow, M.P.H.
Deputy Director

Remaining Reports Due as of April 1, 1998

Organization	<i>The Institute for Rehabilitation and Research</i>		
Grant ID	<i>31313</i>		
Amount	<i>\$172,445.00</i>		
Start Date	<i>3/1/97</i>	End Date	<i>8/31/98</i>

<i>Date</i>	<i>Report Type</i>
<i>6/30/98</i>	<i>Quarterly</i>
<i>9/30/98</i>	<i>Financial</i>
<i>9/30/98</i>	<i>Final</i>

Phone: (609) 452-8701 Fax: (609) 452-9564

Page: 1

FA: RSH PA: DM PO: RG

Grantee: The Institute for Rehabilitation and Research

Project Director: Lex Frieden (713-797-5283)

Grant Number: 031313 for [SCH]

Fiscal Officer : Brian D. Hamilton (713-528-0123)

Budget Period: Mar-01-1998 to Aug-31-1998

Grant Period: Mar-01-1997 to Aug-31-1998

Budget for Year : 2

Revised:

EXPENDITURES

[illegible]

Phone: (609) 452-8701 Fax: (609) 452-9564

Page: 2

FA: RSH PA: DM PO: RG

Grantee: The Institute for Rehabilitation and Research

Project Director: Lex Frieden (713-797-5283)

Grant Number: 031313 for [SCH]

Fiscal Officer : Brian D. Hamilton (713-528-0123)

Budget Period: Mar-01-1998 to Aug-31-1998

Grant Period: Mar-01-1997 to Aug-31-1998

Budget for Year : 2

Revised:

EXPENDITURES

[illegible]

Annual Progress Reports,
Final Grant Report and Bibliography

Grantee Reporting Instructions

THE
ROBERT WOOD
JOHNSON
FOUNDATION

Route 1 and College Road East
Post Office Box 2316
Princeton, New Jersey 08543-2316
www.rwjf.org

THE
ROBERT WOOD
JOHNSON
FOUNDATION

W*e welcome you as a project
director to The Robert Wood
Johnson Foundation community of
grantees. When you receive this booklet,
we suggest that you familiarize yourself
with the requirements for reporting
to the Foundation. We hope they'll
provide guidelines that will be helpful
as you proceed with your program. You
may especially want to read the Final
Narrative Report requirements, which
are slightly different from those of
Annual Progress Reports, to see what
you will have to report to us at the end
of your grant.*

Table of Contents

Annual Progress Reports	4
Final Grant Report	7
Bibliography	12

6. Mass or professional coverage

6a. Print coverage

- (1) "Title of article," (2) in *Title of newspaper or magazine*, (3) Date.

For example:

"More Older Americans Want to Work than Ever Before," in *The New York Times*, June 25, 1995.

6b. Book reviews

- (1) Author of review, (2) "Title of review," (3) a review of *Title of the book*. (4) *Title of the publication carrying the review*, (5) Date of review.

For example:

Luker, Kristin, "Chicago's Mean Streets," a review of *There Are No Children Here*. *New York Times Book Review*, January 20, 1994.

6c. Radio and television coverage

- (1) Name of news show, (2) *Station*, (3) Place (if applicable) (4) Date.

For example:

Dateline, *WNBC-TV*, New York, NY, October 5, 1996. or
National News, *CNN*,
November 12, 1994.

7. Computer readable data and documentation

- (1) "Name of data tape," (2) Organization conducting the research, (3) Dates of research on the tape. (4) Status of its preparation for ICPSR.

For example:

"National Survey of Chronically Ill Americans," Louis Harris and Associates, Inc., March-June 1995. Sent to ICPSR April 1997.

Your **Annual Progress Reports** are the most important substantive documents we ask you to prepare for us during the course of your grant. Together with your financial reports, they are our principal means of staying informed about your project as we internally track, monitor, and report on the activities of the 2,000 grant-assisted programs that are operational at any given time. In the aggregate, grantee reports also provide information useful in our continuing efforts to improve our grant making and monitoring processes. Your Annual Progress Reports are *confidential documents*.

Your **Final Grant Report** takes the place of an Annual Progress Report at the end of the final year of your grant. It is a substantive record of what activities you conducted under your grant, how they met the grant's objectives, and the accomplishments of your program. Your Final Grant Report will be a *public document*. It may be used directly, or information in it used in other documents, as part of our efforts to be accountable for the use of tax-exempt funds, to disseminate information derived from our grants, to respond to inquiries, and for other public information purposes. Your Final Grant Report will thus assist those who can benefit from a record of your experiences and what you have learned.

The **Bibliography** provides us with complete information on the products and presentations (e.g., speeches, workshops, testimony) your program produced, and media coverage received by your program. The Bibliography needs to be updated with each Annual Progress Report and completed with the Final Narrative Report. The Foundation also has an ongoing interest

in the effects and accomplishments of your program over the long run and we would welcome any updates on the continuation, dissemination, or replication of your work after your grant is closed.

Please submit three copies of each Annual Progress Report and Final Grant Report and their accompanying Bibliographies to the Financial Monitoring Office. They will work with you on all budgetary aspects of your grant. They will in turn forward copies to Central Files for your permanent grant file and to your Program Officer.

If you are experiencing problems or unexpected successes at any time during your grant, please alert your Program Officer and Financial Analyst/Officer about them as soon as they become apparent to you, rather than waiting for the Annual Progress Report. Any changes in objectives or methodology must be approved in writing by your Program Officer in conjunction with your Financial Analyst/Officer.

Standard Reporting Format

We have devised a standard reporting format for each kind of report built around a series of questions. We designed it to provide detailed information about the progress of your project in meeting your objectives and goals, and, for the Final Report, to provide essential information about the results and significance of your project. Many of the questions for Annual and Final Reports are the same, which should minimize the effort required to prepare them. When you write your Final Grant Report, please include all activities and accomplishments of the final year of your grant.

4. Audio-visual, WWW, and other electronic media

Include the following information, as applicable:

- (1) Title (2) (Type of item being described: e.g., film, radio tape, Web site, etc.). (3) Place of publication. (4) Publisher, (5) Date of publication. (6) Number of copies produced; (7) Number of copies distributed/sold to date.

For example:

*Hospital-Sponsored Group Practice:
Ingredients for Success* (150 minute audio cassette). Chicago: American Hospital Association, 1983. 400 copies produced; 200 sold to date.

5. News conferences and briefings and news releases

Include the following information, as applicable:

5a. News Conferences

- (1) Press Conference: Subject matter, (2) Where held, (3) Date when held, (4) Attendance.

For example:

Press Conference: Survey results from Louis Harris and Associates, Inc. survey on older workers, Washington, D.C., June 19, 1995. Attended by over 100 journalists.

5b. News Releases/Packets

- (1) News Release/Package: subject matter, (2) When mailed to how many people.

For example:

A news packet on the Louis Harris survey of older workers was mailed on June 15, 1995 to over 400 newspapers, radio, and television stations.

1d. Survey/research instruments

(1) "Title of survey." (2) Organization that fielded the survey, (3) date first fielded. (4) number of requests for instrument (if it is being released).

For example:

"The Older Workers Survey." Louis Harris and Associates, Inc., fielded May-August 1995.

2. Conferences, meetings, and workshops

(1) "Title of conference," (2) Date, (3) Place. (4) Attended by how many people from how many organizations. (5) Examples of institutions attending (6) Number of Presentations given: (7) Title, (8) Presenter, (9) Title of speech. etc.

For example:

"Medicaid in the 21st Century," May 22-25, 1996, Washington, D.C. Attended by 600 individuals from 350 organizations including XX and XX. 15 presentations were made: David Helms, "State Efforts to Reform Medicaid." Karen Davis, "Who Medicaid Serves and What Services it Provides." etc.

3. Speeches, testimony, legislative briefings, and other presentations

(1) Name of presenter(s). (2) "Title of presentation," (3) Title of conference or meeting or name of governmental body testimony was made to, (4) Name of the organization holding the conference. (5) Place meeting held or testimony given, (6) Date meeting held or testimony given.

For example:

Petersmeyer, Gregg. "How to Find Community Entrepreneurs," at the Annual Meeting of Grantmakers In Health, Atlanta, GA, September 1995.

Narrative Text

Limit your narrative to a maximum length of 12 pages, including any charts and tables. The Bibliography, if provided, does not count in this 12-page limit. See page 12 for more information about the Bibliography. Type the first page of the Report on a sheet of your institution's or organization's letterhead stationery. Date the page, head it ANNUAL PROGRESS REPORT (Year 1,2,3, etc.), or FINAL GRANT REPORT followed by:

- the title of your project,
- its RWJF grant identification number, and
- the dates covered in the report, which would be the entire grant period for the Final Report.

Use the eight questions on pages 4-6 as bold subheads for the body of your Annual Progress Report. Similarly, use the 10 questions on pages 7-11 as the bold subheads for the body of your Final Grant Report. Support your answers with quantitative data where they are available and appropriate; provide other supportive evidence where requested. You may use "None" and "Not applicable" where appropriate. You may pose and answer any other questions that seem relevant after answering our questions, provided the Report does not exceed the 12-page limit.

Except for the Bibliography and the sample materials requested (see p.12), do not include appendices, attachments, exhibits, or other addenda to your Report. If you wish to share additional items of information with us, send them under separate cover to your Financial Analyst/Officer.

Bibliography

The format for the bibliography is described in its section on page 12.

Annual Progress Reports

The Eight Questions

1. What were the project's objectives and how has the project met them in this year?

Be as specific as possible. Writing down each of the project's original objectives approved by the Foundation, explain how each has been met in this reporting period or the plans for it to be met in the remaining grant period. If it was met in a previous reporting period, state that, and what has happened as a result.

If objectives have been changed, describe the reason for the change, what the revised objective is, and the date and means by which the Foundation approved the revised objective (letter from a Foundation staff member, e-mail, etc.). While this information should be on file with the Foundation, we request you include it here for purposes of clarity.

If an objective has not been met that was projected to have been met during this time period, explain what happened and why.

If there's been any additional accomplishments beyond the original/revised objectives, describe them, and how and why they came about.

Please make sure you include the following information as appropriate to your project:

- If it is a service project, indicate the number of people served during the year and being served currently, and the services that are provided, where, and how. If the project is only in the planning or development stage, indicate what has been accomplished to date.
- If it is a research project, describe exactly where the project is in the research process and what has been accomplished during the year, including any preliminary findings.

Bibliography Entry Categories and Formats

1. Publications

1a. Books and reports

(1) Name of author(s) or editors(s). (2) *Title of book or report.* (3) Place of publication: (4) Publisher, (5) Year of publication. (6) number of copies sold or requested to date of report.

For example:

Egdahl, Richard, and Paul Gertman, (eds). *Quality Assurance in Health Care.* Germantown, MD: Aspen Systems Corporation, 1994. 500 copies sold to February 1997.

1b. Book chapters

(1) Name of author(s) of chapter. (2) "Title of chapter." (3) *Title of book in which chapter appears.* (4) Edited by name(s). (5) Place of publication: (6) Publisher, (7) Year of publication.

For example:

Ginzberg, Eli. "Summing up." *The Regionalization of Personal Health Services.* Edited by Ernest W. Saward. New York: Milbank Memorial Fund, 1975.

1c. Journal articles

(1) Name of author(s). (2) "Title of article." (3) *Title of journal.* (4) Volume number (5) (Issue number): (6) Inclusive pages, (7) Complete date of issue. (8) number of reprints your organization has disseminated.

For example:

Aday, Lu Ann. "The Impact of Health Policy on Access to Medical Care." *Milbank Memorial Fund Quarterly.* 54(2):215-233, Spring 1976. 300 copies disseminated to February 1997.

Bibliography

If your grant has resulted in any dissemination activities, please include a bibliography with your Annual Progress Report and Final Grant Report. The Bibliography should include *all* dissemination from your project to date.

The bibliography does not count toward the 12-page limit for your report. Please follow the formats given below, listing each item chronologically with the most recent items last.

Please include works in progress or submitted for publication as well as those that have been accepted for publication and published. For submitted work, include the date of submission and identify the journal to which the article was submitted. For works in progress, include the expected date of completion.

Enclose two copies of each disseminated product produced under your grant (manuscripts completed but not published, articles, books, reports, speeches, brochures, electronic materials, radio tapes, videos, press releases and packets, an index of WWW site information, etc.) and of all print media coverage (book reviews, print news stories). If a story appeared in AP or other news wire service, send two copies of one story and a listing of all papers where it appeared in the bibliography. Label each item supplied to the Foundation with your grant's five-digit identification number. All these materials should be sent to the Financial Monitoring Office with your report. If you want your program officer to have his or her own copies, please send them separately and directly, in addition to the copies to the Financial Monitoring Office.

- If it is a technical assistance and direction grant (TAD), summarize the assistance that has been provided to program sites during the year, mentioning anything noteworthy, and progress toward meeting the goals outlined in the work plan, if you provided one.

2. Have any internal problems been encountered during this year that are related to the project's design, collaborations, staffing, operations, or other project factors?

Describe them and what has been undertaken to solve them. If these problems continue to exist despite your best efforts, indicate that. If no problems have been encountered, indicate that.

- Do you anticipate delays in completing objectives because of these factors?
- Is there something the Foundation could do to assist you?

3. Are there problems or successes caused by factors external to the project?

- Is the project well timed to take advantage of the external environment? If so, in what way? Or, has it suffered from its timing? How?
- Are there unanticipated changes in external factors that are causing problems or unanticipated successes? In what way?
- If the changes are negatively affecting the project, how are you attempting to cope with them?
- Is there something the Foundation could do to assist you?

4. If you are working in collaboration with other organizations, or depend on other organizations or institutions to meet the objectives of this project, how are those relationships working?

Please describe the high points and shortfalls in such arrangements during this year, with an eye to offering useful insights to the Foundation and other grantees with similar arrangements.

5. Have there been any key dissemination activities during the past year?

If there have, please describe them and their significance, (e.g., publication in a major journal, speech at a major conference, an unusual and important request for copies of a book or a speech). Then describe plans you have for the future.

If you are required to produce computer readable data and documentation, describe the status of tape preparation.

Note that a listing of all dissemination activities in the following categories is called for in the Bibliography section:

- Publications
- Conferences, meetings, and workshops
- Speeches, testimony, legislative briefings, and other presentations
- Audio-visual, WWW, and other electronic media
- News conferences and briefings and news releases
- Mass or professional media coverage including print, radio, and television
- Computer readable data and documentation

6. Does the project have other sources of support?

If so, please give the institution(s) and approximate dollar amount.

Also list institutions giving in-kind support and what has been given (e.g., space, computer). Please indicate if the total support for the project is more than expected, or less than requested.

7. What are your plans for the project next year?

Please include a description of the objectives you will focus on; actions you will take; and other people, groups, or organizations you will involve.

- Describe any anticipated problems and what you intend to do to address them. Can the Foundation assist you in solving them?

8. How do you see the Foundation's role?

Have the Foundation's policies or operations helped or hindered the project to date? Are there changes to our operations that could facilitate your work in the future?

- Has it created a new model for delivering services or conducting research?
- Has it informed the further work of other researchers?

8. What lessons did you learn from undertaking this project?

What lessons does the success or shortfall of the project have for other grantees attempting similar efforts? What would you recommend to grantees to emulate and/or to avoid?

9. What are the post-grant plans for the project if it does not conclude with the grant? Please include a description of the following that are applicable:

- Changes in operations and scope
- Replication or use of findings
- Other institutions you will involve
- Plans to support the project financially, including grants you are seeking and/or a business plan to become self-supporting
- Dissemination plans

If, after the grant is closed, you have a publication, receive media coverage, or other significant dissemination, we would appreciate it if you would send us a description and two copies.

10. How do you see the Foundation's role?

Have the Foundation's policies or operations helped or hindered the project in any way? Are there changes to our operations or dissemination activities that might have facilitated or improved the project?

If you are required to produce computer readable data and documentation, indicate when you expect the tape to be sent to ICPSR.

Note that a listing of all dissemination activities in the following categories is called for in the Bibliography section:

- Publications
- Conferences, meetings, and workshops
- Speeches, testimony, legislative briefings, and other presentations
- Audio-visual, WWW, and other electronic media
- News conferences and briefings and news releases
- Mass or professional media coverage including print, radio, and television
- Computer readable data and documentation

6. Has the project had other sources of support?

If it has, please describe them, how much funding each has provided, and when these funds were received. Also include in-kind support. Please indicate if the total support for the project was more than expected, or less than requested.

The next set of questions are seeking information on the effects of your project, your post-grant plans and lessons learned.

7. What was the significance of the project's accomplishments?

Please provide evidence for all statements about significance.

- Has the project contributed in some significant way to general knowledge about a subject? To a change in conventional wisdom? To changes in policy at the federal, state, or local level? To the public's access to information?

Final Grant Report

The Final Grant Report, rather than an Annual Progress Report is filed at the end of the last year of your grant. The first six of the Report's 10 questions are basically the same as those you have answered in each of your Annual Progress Reports. This time, however, we need you to answer them for the entire project, folding the final year's activities into your responses.

NOTE: This report will be treated by the Foundation as a public document and may be distributed in response to public inquiries, posted on the Foundation's World Wide Web site, and distributed in other ways as part of the Foundation's public information and dissemination efforts. In view of this, you may submit a supplemental letter with any information you want treated with greater confidentiality.

The 10 Questions

1. What were the project's objectives and how have the accomplishments of the project met them?

Be as specific as possible. Writing down each of the project's original objectives approved by the Foundation when the grant was made, explain how the accomplishments of the project met the objectives of the grant.

If original objectives were changed, describe the reason for the change, what the revised objective was, and the date and means by which the Foundation approved the revised objective (letter from a Foundation staff member, e-mail, etc.). While this information should be on file with the Foundation, we request you include it here for purposes of clarity.

If an objective has not been met that was projected to have been met during the grant, explain what happened and why.

If there were additional accomplishments beyond the original/revised objectives, describe them, and how and why these activities were undertaken.

Make sure that you describe **what the project actually did**. Be as specific as possible. Cover the areas below that are applicable to your project:

- If you conducted a review of the literature to help direct your project, describe key findings, and how they were used.
- If you worked in collaboration or cooperation with other organizations or institutions, describe those arrangements and their importance to the project.
- If it was a technical assistance grant (TAD), describe the assistance provided, to whom, when, and how that facilitated the work of different program sites.
- If it was a service project, indicate the number of people served in total during the project, the services that were provided, where, over what time period, and how. If services are continuing, indicate the number of people currently being served.
- If it was a research project, describe the subject matter of the research, the time period, the universe, and the response rate (if applicable). Please include the research instrument if you developed it under this grant or a previous Foundation grant. If your research depended on existing data, describe its accessibility; if it needed to be integrated with data collected by this grant, describe the ease or difficulty of that integration.
- Describe the major findings of your research. Use a bullet for each key finding.

2. Were there internal shortfalls or limitations in the project's funding level, design, collaborations, staffing, operations, or other project factors?

If so, what actions did you take to solve these problems? Were they expected or unexpected problems? What was the effect on the project? If no shortfalls or limitations have been encountered, indicate that.

3. Were there problems or successes caused by factors external to the project?

- Was the project well timed to take advantage of the external environment? If so, in what way? Or, has it suffered from its timing? How?
- Were there unanticipated changes in external factors that caused problems or unanticipated successes? In what way?
- If the changes negatively affected the project, how did you attempt to cope with them?
- Was there something the Foundation could have done to assist you?

4. If you worked in collaboration with other organizations, or depended on other organizations or institutions to meet the objectives of this project, how did those collaborations work?

Please describe the high points and shortfalls in such arrangements, with an eye to offering useful insights to the Foundation and other grantees with similar arrangements.

5. With a perspective of the entire project, what have been its key dissemination activities?

Please describe them and their significance, (e.g., publication in a major journal, speech at a major conference, an unusual and important request for copies of a book or a speech). Then describe plans you have for the future.

THE ROBERT WOOD JOHNSON FOUNDATION NATIONAL PROGRAM SITE BUDGET PREPARATION GUIDELINES

OVERVIEW

An important component of your grant application is the preparation of a detailed budget and budget narrative. This document links the funding you have requested with specific elements of the project you have proposed. Therefore, the budget you propose should be an appropriate and accurate projection of the program expenses.

Policy guidelines established by the Foundation's Board of Trustees usually preclude support for:

- ongoing general operating expenses or existing deficits
- items for which third-party reimbursement is available
- endowment or capital costs, including construction, renovation, or equipment
- basic biomedical research
- conferences or symposia, publications or media projects - unless they are integrally related to the Foundation's program objectives or an outgrowth of one of its grant programs
- research on unapproved drug therapies or devices
- international programs or institutions
- direct support to individuals
- costs incurred by a grant applicant for the specific purpose of writing a proposal, or for the instruction or direction of its own personnel in such writing.

Your proposed budget will be reviewed in detail and negotiated to ensure that it meets the goals and objectives of your proposed project and that it is consistent with Foundation policies. Therefore, during budget negotiation, your budget may need revisions.

During the budget negotiation process, Foundation staff may deem it appropriate to eliminate a line item or support only a percentage of the funding requested for a particular line item. In these cases, you may need to identify and specify other sources of support.

Applicants should read carefully the "Request for Project Support and Conditions of Grant" form, which must be signed as part of your application package. This document contains information regarding the legal, financial, communications, and program responsibilities of a grantee, and becomes binding upon you if you receive a grant.

Any questions concerning the budget preparation for a proposal to be submitted to The Robert Wood Johnson Foundation can be directed to the Treasurer's Office at (609) 452-8701.

PLEASE NOTE: The last section of this document (*Attachments A and B*) outlines The Robert Wood Johnson Foundation Financial Reporting/Budgeting Practices and Grant Budget Revision Guidelines.

GUIDELINES

The budget must be independent of the proposal document. If information is contained in your proposal that will strengthen the budget narrative provided, please reference the page number. This, however, cannot substitute for a separate and complete justification for each line item in the budget.

The budget should be divided into two parts: a *line-item budget* and a *budget narrative*.

The sample line-item budget attached shows the format in which costs associated with the proposed project should be identified. Not all line items will be applicable to your proposal, and, in some cases, you will need to add line items. Note: Line items entitled "Miscellaneous" will not be funded. If your institution's accounting system does not adhere to the line items listed on the sample line item budget (page 4 of this document), you may present your budget using your institution's format.

The budget narrative must include an explanation for *every* line item. In general, each narrative statement should describe, in as much detail as possible:

- what the specific item is
- how the specific item relates to the project
- how the amount shown in the budget was arithmetically determined

For grant proposals that require funding for more than one year, the budget must be divided into twelve-month periods. The principal exception is projects that are for uneven periods. For example, if a grant lasts 27 months, you should prepare two twelve-month budgets and one three-month budget. The three-month budget can be either at the beginning or the end of the proposed grant period. A line-item budget and budget narrative should be prepared for each year/period for which you are requesting Foundation support, and a consolidated line-item budget should be prepared for the *entire* proposed grant period.

A column labeled "Other Support" is included in the sample line item budget. This column is to be completed if other sources of funds are to be applied to the line items in the budget. For example, if a Project Manager is to be partially funded by the Foundation and partially or completely by his/her institution, the institution's commitment should be listed as "Other Support." All sources of non-Foundation financial support should be identified in the budget narrative.

The following pages of this document contain a sample line-item budget as well as budget narrative guidelines. *Please read them carefully.*

**THE ROBERT WOOD JOHNSON FOUNDATION
SAMPLE LINE ITEM BUDGET**

Grant Period: (from ___/___/___ to ___/___/___)

Budget Period: (from ___/___/___ to ___/___/___)

PROJECT YEAR 1 2 3 4 Consolidated (please circle)

I. PERSONNEL:

Name	Position	Base Salary	% Time	Total	RWJF Support	Other Support
------	----------	-------------	--------	-------	--------------	---------------

Fringe Benefits (_____%)

SUBTOTAL

II. OTHER DIRECT COSTS

OFFICE OPERATIONS

Supplies

Duplicating

Telephone

Postage

Equipment Rental

Service Agreement(s)

COMMUNICATIONS/MARKETING

SOFTWARE

COMPUTER TIME

MEETING COSTS

TRAVEL

SUBTOTAL

III. INDIRECT COSTS

IV. EQUIPMENT

**V. CONSULTANT/CONTRACTUAL
AGREEMENTS**

TOTAL

BUDGET NARRATIVE

Listed within each category is a description of the information that we require in order to review your proposed budget. Each category is organized by Roman numeral corresponding to the sample line item budget form.

Other Support: Please itemize the amounts and sources of cash and in-kind support.

- I. **PERSONNEL:** In addition to the information required on the sample line-item budget form, include a detailed description of the activities of *each* position as it relates to the project. For example:

The Project Director is accountable for planning, organizing, and directing the implementation and operations of this project. Specific responsibilities include directing staff, orientation, training, counseling, evaluation, and discipline in accordance with department standards. Directs the implementation and operations, distributes work, directs and personally handles public relations, estimates costs of programs, develops the budget, oversees and negotiates contracts with subcontractors, monitors and assesses project performance and performs other related non-clinical duties. The Project Director directly supervises three case managers, one nurse clinician, and a secretary.

The Case Manager provides comprehensive case management services to residents and potential residents of housing and supported work program. Duties include needs and skills assessment, service planning, agency linkage and liaison, resource development, family liaison and support, transportation coordination and assistance, services evaluation, and record keeping. The maximum caseload will be thirty clients per case manager with a projected client turnover rate of 20% every six months. Forty-two clients will be served annually per case manager.

Fringe Benefits: Indicate what benefits will be provided and how the amount was calculated. If different rates were used for different individuals, your narrative should contain a table which summarizes the calculation for each individual.

Sample Table:	Salary	Fringe Rate	Fringes
Project Director	\$40,000	.25	\$10,000
Case Manager	25,000	.20	5,000
Research Assistant	20,000	N/A	-0-
			Total fringes <u>\$15,000</u>

II. OTHER DIRECT COSTS

Office Operations: The projected expenditures for Supplies, Duplicating, Telephone, Postage, Equipment Rental and Service Agreement(s) should be provided separately along with a description of how estimates for each were determined. For example:

Supplies - the requested supply budget is \$2,500 in Year 01. This includes \$1,000 for office supplies such as tape, stationery, fax paper, pens, pencils, and business cards. Additionally, \$1,500 is budgeted for computer supplies to support the component of our project which involves data analysis.

Duplicating - copying of project correspondence and reference materials to be utilized in the training of the Home Health Aides. The total requested budget is \$2,100 per year.

Telephone - there are two separate costs associated with this line item: the installation of three incoming lines, and long distance calls. Three incoming lines will be installed for the Project Director, Administrative Assistant, and Program Manager. The estimated cost is \$200 total. The long distance calls will be made for the 50-state survey. This entails the initial interview call and one follow-up call. The anticipated costs are \$4,000. Therefore, the total telephone budget is \$4,200.

Postage - the total requested postage budget is \$2,500. This includes mailing routine correspondence as well as the community health assessment questionnaire.

The questionnaire is an integral component of our activities in Year 01 as outlined on page 22 of our proposal. The total number of questionnaires to be mailed are 7,500 @ first class rate = \$2,175. The \$325 balance is for mailing of routine correspondence.

Equipment Rental - We are requesting the rental of a copy machine for the purpose of copying daily correspondence and the necessary reports to be sent to the Foundation. Our vendor has provided us with an estimate of \$200 a month.

Service Agreement(s) - We will require service contracts for a copy machine and typewriter in order to maintain this equipment in proper working condition. This equipment is essential to the secretary in order to perform tasks outlined in her job description. Total costs are \$1,400 (\$200/year for typewriter and \$100/month for the copy machine).

Communications/Marketing - Funds can be allocated to increase awareness and visibility as well as promote your project. In addition costs associated with the printing of brochures, newsletters, press kits, etc., should be listed along with a description. For example:

Billboards and public service announcements will be developed and placed or aired in our service area. Since our target population (age 13-18) does not generally read the newspaper, we believe that this is the best way to reach the target population. Public service announcements are part of the community bulletin board; therefore the local radio station will air our announcement at no charge. However, billboard advertising will cost \$450 a month for six months. Total cost is \$2,700.

Two brochures will be printed describing Fetal Alcohol Syndrome. One will be printed in Spanish, and one in English. The five Case Managers will each be given 2,000 brochures to utilize during outreach activities. The total cost for typesetting and printing 10,000 brochures is \$7,000.

In addition, \$500 for two days of media training for the project director is essential to increase the visibility of the project in the community.

Software - itemize the software requested and include a statement outlining how the software will be used to fulfill project goals. For example:

A customized software package will be developed to collect data which will allow us to link maternal and neonatal outcomes with prenatal care. Additionally, we will track newborn admissions and transfers. The software vendor's estimate is \$850.

Computer Time - costs associated with processing information on a mainframe computer should be explained as they relate to the objectives of the grant. For example:

We will require 125 hours of mainframe time at \$70 per hour totaling \$8,750. The requested number of mainframe hours is necessary due to the multiple data sets to be merged and analyzed.

Meeting Costs - projected expenses for meetings should be included in this line item. Such expenses would include meeting room rental, audiovisual equipment rental, slide presentation costs and meals. For example:

The total cost for the Steering Committee meeting is \$390. This includes \$240 for lunch (7 committee members and 5 project managers), \$100 room rental and \$50 for audiovisual equipment. The purpose of this meeting is to convene the five project managers to provide them with technical assistance. Each committee member will lead a workshop on their area of expertise.

Travel - the projected expenditures for Project Staff and Consultant Travel should be outlined.

Project Staff Travel: The projected expenditures for local and non-local travel should be described in this section. The basis for the calculation as well as the purpose for all travel should be provided. Travel estimates for local travel should be based on your institution's current policies - for example, \$0.27/mile.

As a rule, for non-local travel, the Foundation allows up to \$975 for a one night-one day meeting and \$1,140 for a two night-two day meeting where air travel is necessary. This figure includes airfare, lodging, meals, and ground transportation. **If you are able to identify the specific destination and rates for airfare and lodging, you should include the actual amounts in your budget and narrative.** For example:

Local Travel - as outlined in the job description, the three Case Managers will travel daily between the Project Office and the community for outreach activities.

Additionally, they will travel to the local Office of Human Services, clinics, and other resource agencies. We have estimated that they will each travel 100 miles/week X \$0.25 = \$25.00/week. Therefore, the total travel cost for three Case Managers per year is \$3,900.

Non-local Travel - two site visits by the Project Director to existing community-based programs serving an elderly clientele with prospective payment systems and/or full case management services. The Project Director will be exploring possible applications in the areas of product design, marketing techniques, and utilization. Travel estimate is based on \$975/trip for a 1-night stay giving a total of \$1,950.

Annual Meeting Travel: You should budget a 2-night stay (\$1,140) for 2 project staff to attend the National Program's annual meeting each year (total \$2,280 per year), unless otherwise directed by your National Program Office.

Consultant Travel: As with Project Staff Travel, the travel costs should be outlined in detail, including destination, purpose and the basis for calculation. However, the actual work to be performed should be detailed under "Consultant/Contractual Agreements." For example:

As outlined in the narrative for Consultant/Contractual Agreements, Dr. Smith will meet with the staff of two hospitals (one in Boston, and one in Philadelphia) and will also require one trip to an insurance company to discuss malpractice issues. The travel estimate is based on three 1-night-stay trips X \$975 = \$2,925.

- III. **INDIRECT COSTS:** Indirect costs may be calculated up to 9 percent *on budget* categories I and II; they *should not* be calculated on the amounts budgeted for Equipment and Consultant/Contractual Agreements, items IV and V.

This line item is intended to cover grant-related costs that are not easily identified, but are necessary to conduct the grant - i.e., reporting costs, payroll processing, utilities, space rental costs, etc. *This rate is non-negotiable.*

- IV. **EQUIPMENT:** Although Foundation grants are not made for the sole purpose of funding capital costs, a limited amount of equipment may be requested if appropriate for the accomplishment of program objectives. Itemize the equipment requested and include a statement outlining how the equipment will be used to fulfill project goals. You should explore the option of purchasing vs. leasing/rental, and explain your choice. Generally, the Foundation will support only a portion of the equipment line item. Therefore, you should explore whether other sources of funds can be obtained for equipment. For example:

We are requesting an IBM compatible personal computer and printer. We do not currently have access to a computer system. Obtaining the computer will assist us in meeting our program objectives by allowing us to undertake the following: analyze and manage the survey results, collate the demographics of our clients, respond to requests for information, and track client progress and adherence to scheduled appointments. The total cost is \$4,500 (\$2,500 for the personal computer and \$2,000 for the printer) of which we are requesting Foundation support of \$2,250 or one-half. The clinic will assume the remaining costs.

V. **CONSULTANT/CONTRACTUAL AGREEMENTS**

Consultant: The need for each consultant must be outlined in detail. A workplan for each, including the tasks to be accomplished, should be included. Fees paid by the Foundation are not to exceed \$500/day for a full day of work. If the daily rate charged by any particular consultant is more than \$500, you will need to identify other sources of support. For example:

Consultant Costs are budgeted at \$6,000/year for the participation of Dr. Smith. He will provide expertise in the field of hospital malpractice and serve as our liaison to hospital risk managers and insurers. He will participate in project meetings, refinement and fielding of the questionnaire, review of research methods and draft papers, and work with underwriters and other companies to implement risk-adjusted premiums, as appropriate. The \$6,000 estimate is based on twelve days/year at \$500/day.

Contractual Agreement(s): For each proposed contract for which you request Robert Wood Johnson Foundation support, you should provide an explanatory paragraph that describes in detail the services to be provided. If possible, you should also provide a separate line item budget and budget narrative. If the specifics of the contract are not available during budget development, you will need to submit a fact sheet (or a copy of

the actual contract) once you have identified the contractee. The fact sheet (or actual contract) should outline the following:

- * contractee
- * dates
- * dollars
- * tasks/deliverables

The Foundation should not be listed as a party to the contract. The grantee maintains fiscal responsibility for its contracts which includes reporting expenses associated with the contract to the Foundation.

s:\nldbudgd.doc

ATTACHMENT A

ROBERT WOOD JOHNSON FOUNDATION FINANCIAL REPORTING/BUDGETING PRACTICES

FINANCIAL REPORTING AND OVEREXPENDITURES

You are required to report expenditures on a line-item basis corresponding to your approved budget. However, you may overexpend an individual line item provided you do not exceed the approved budgeted CATEGORY (Personnel, Other Direct Costs, Equipment, and Consultant/Contractual Agreements) total plus 5 percent. For example:

<u>PERSONNEL</u>	<u>APPROVED BUDGET</u>	<u>TOTAL EXPENDITURES</u>	<u>VARIANCE</u>
Project Director	45,000	48,000	(3,000)
Secretary	20,000	18,000	2,000
Research Asst.	30,000	35,000	(5,000)
Fringe Benefits	19,000	18,700	300
SUBTOTAL	114,000	119,700	(5,700)

As this example illustrates, the expenditures reported in the Personnel budget category do not exceed the approved budget category amount by more than 5 percent. Therefore, no explanation or budget revision would be required.

- Indirect costs cannot exceed 9 percent of actual direct costs reported.
- Although you may overexpend any CATEGORY by 5 percent you must remain within the total approved budget per year.

CONTRACTUAL AGREEMENTS

If a fact sheet (or copy of the actual contract) was not provided at the time you negotiated your grant budget, the following information is required to be submitted prior to expending funds against a contract line item:

- fact sheet outlining the following:
 - * contractee
 - * dates
 - * dollars
 - * tasks/deliverables
- or, a copy of the actual contract.

ATTACHMENT A

(continued)

The Foundation should not be listed as a party to the contract. The grantee maintains fiscal responsibility for its contracts which includes reporting expenses associated with the contract to the Foundation.

INTEREST INCOME

Interest earned on Robert Wood Johnson Foundation funds should not be reported to us. However, we encourage you to use these funds to benefit the project supported by the Foundation.

UNEXPENDED FUNDS

Grantees may request that funds unexpended from previous budget periods be used in subsequent budget periods. A revised budget and budget narrative should be submitted that outlines the use of these funds.

GRANT EXTENSION

Grantees may request that funds unexpended from previous budget periods be used to extend the award beyond the original end-date. The proposed activities must be consistent with the original objectives of the award. An explanation regarding the activities to be undertaken during the extension period should be provided, as well as a separate budget and budget narrative. The dates of the extension period should be explicitly stated.

Grant Budget Revision Guidelines are available to assist you in preparing a revised budget and/or extension request. Any questions related to this document or other general financial questions should be addressed to the Treasurer's Office at (609) 452-8701.

s:\bgtpract

ATTACHMENT B

ROBERT WOOD JOHNSON FOUNDATION GRANT BUDGET REVISION GUIDELINES

Revisions to your approved grant budget must be requested when changes in your grant project result in the need for additional line items, and/or you anticipate spending in excess of the approved budget categories by more than 5 percent. These categories include Personnel, Other Direct Costs, Equipment, and Consultant/Contractual Agreements. The guidelines that follow will assist you in preparing your budget revision. If you have any questions, please contact the Treasurer's Office at (609) 452-8701.

Your budget revision request should include a **NARRATIVE** describing those line items you are requesting a change. A **LINE-ITEM BUDGET** should be submitted in a format that displays your entire original budget, and your requested changes. Please be sure to identify the budget period, and illustrate your reallocation as demonstrated below. In addition, you should include a narrative that explains how the revised budget item(s) relate to the project and how the proposed amount(s) were determined.

Grantee: Community Health Coalition Grant #12345
BUDGET PERIOD - January 1, 1995 through December 31, 1995

<u>Line Items</u>	<u>Approved Amount</u>	<u>Revision Proposed Request</u>	<u>Expenses Budget</u>	<u>Incurred (to date)</u>
PERSONNEL				
Project Director	40,000	- 3,000	37,000	9,250
Case Manager	-0-	+25,000	25,000	-0-
Secretary	25,000	-0-	25,000	3,000
OTHER DIRECT COSTS				
Duplicating	2,500	- 1,500	1,000	750
Supplies	1,000	-0-	1,000	250
Marketing	8,000	- 3,500	4,500	2,500
Travel	7,000	- 5,000	2,000	-0-
CONSULTANT/CONTRACTUAL				
XYZ Corp.	40,000	-12,000	28,000	28,000
Health Care Corp.	5,000	-0-	5,000	-0-
TOTAL	128,500	-0-	128,500	43,750

ATTACHMENT B
(continued)

THE FOLLOWING POINTS WILL ASSIST YOU IN DEVELOPING YOUR REVISION.

- (1) Submit your revision in a format that displays your entire budget and your requested changes.
- (2) Line items for which expenses have been incurred cannot be deleted from your budget. The line item must state the actual expenses incurred as of the date of the revision.
- (3) Any addition or deletion of approved items should be explained in your budget narrative.
- (4) Budget revisions may require recalculation of the amount approved for indirect costs. The Foundation indirect cost policy allows 9 percent of expenses budgeted against the categories Personnel and Other Direct Costs. Indirect costs should not be calculated on the amounts budgeted for Equipment or Consultant/Contractual. Indirect costs are intended to cover incidental expenses related to operating the grant, including space rental.
- (5) Revisions to personnel line items may change the approved amount for fringe benefits. The proposed fringe benefit amount should be recalculated and stated in the narrative section.
- (6) In some circumstances, a revision of your budget can be requested over the telephone. This method of approval is generally related to revisions in the "Other Direct Costs" category.

3) Joe Syon (left message with Rev. Brown; not listed in phone book)

Bob Sale home: (713) 782-9753

Ronnie Bender still works at TIRR 11-7 797-4511 (5th floor)

Robert Sullivan ofc: 861-4914 X-35; home: 738-0657; pager: 861-2792

Delma: Charles Rossi: home: 665-4349



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104

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Reorienting Disability Research



National Council on Disability

April 1, 1998

National Council on Disability
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Reorienting Disability Research

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This document is free of charge and available in alternative formats.

The views contained in this report do not necessarily represent those of the Administration, as this document has not been subjected to the A-19 Executive Branch review process.



NATIONAL COUNCIL ON DISABILITY

An independent federal agency working with the President and Congress to increase the inclusion, independence, and empowerment of all Americans with disabilities.

LETTER OF TRANSMITTAL

April 1, 1998

The President
The White House
Washington, DC 20500

Dear Mr. President:

On behalf of the National Council on Disability (NCD), I am pleased to submit a report entitled *Reorienting Disability Research*. The report synthesizes recommendations by researchers and consumers toward a disability statistics policy that is more meaningful and useful in light of the paradigm shift precipitated by the Americans with Disabilities Act of 1990, which NCD originally proposed.

For many years, disability research has appeared to be essentially a scientific exercise, based on academic procedures applied in an area of health care. People with disabilities have learned, however, that underlying values and assumptions have guided research in ways that are not necessarily important or helpful to them as the ultimate beneficiaries. Choices are made, either consciously or not, at each stage of research design, collection, and dissemination that affect the utility of the research to individuals with disabilities. Given limited federal resources, which questions should be studied? How should they be studied? What should be done with the results?

This report recommends action steps to reorient the answers to these questions based on the thinking that disability is a natural part of the human experience; that people with disabilities should participate in the production and consumption of research about them; and that disability data should be an integral part of population statistics and socioeconomic measures of progress. NCD stands ready to work with you and stakeholders outside the government to see that the agenda set out in the attached report is implemented.

Sincerely,

Marca Bristo
Chairperson

(The same letter of transmittal was sent to the President Pro Tempore of the U.S. Senate and the Speaker of the U.S. House of Representatives.)

NCD MEMBERS AND STAFF

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ACKNOWLEDGMENT

The National Council on Disability wishes to express its appreciation to Jane West for her assistance in drafting this report.

BACKGROUND

This document is the product of a yearlong initiative sponsored by the National Council on Disability (NCD) and the National Institute on Disability and Rehabilitation Research (NIDRR) of the U.S. Department of Education. It was prompted by the National Council on Disability's Disability Policy Summit in April 1996 and subsequent release of the report *Achieving Independence: The Challenge for the 21st Century* in July 1996. At the Policy Summit, people with disabilities articulated their keen interest in disability statistics and identified a need for changes in federal data collection activities. Their interest in disability statistics reflects their recognition that such data are often used in policy decisions and that better data will enhance their ability to pursue changes in government policies that will benefit people with disabilities. Recommendations to improve data collection are included in *Achieving Independence*.

NCD was prompted by the disability community to go beyond the *Achieving Independence* recommendations and initiate in-depth dialogue with policy makers, people with disabilities, and researchers about how such changes could be achieved. It was determined that the next step would be a document targeted to federal disability policy makers in Congress and the Administration, outlining specific action steps that could be taken to improve the nation's disability data collection activities. NIDRR initiated the development of this document by funding a synthesis of disability data recommendations that had been made by various bodies in the recent past. This synthesis was reviewed by members of the Interagency Subcommittee on Disability Statistics and used as the basis for a meeting held on June 13, 1997, in Washington, D.C. More than 45 researchers, people with disabilities, and policy makers attended that meeting, entitled "How Consumers Can Maximize Their Influence on and Use of Disability Data: A Dialogue Among Consumers, Data Producers and Data Analysts." A significant portion of the meeting was focused on discussing the synthesis and offering suggestions for improvement. This report is the product of that meeting.

It is intended to inform policy makers in Congress and the Administration about action steps they could take to improve disability data collection activities of the Federal Government. While the

report does not purport to represent consensus among the disability community, researchers, and policy makers, it does offer a synthesis of recent thinking on this topic.

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INTRODUCTION

Data related to people with disabilities have increasingly gained the interest of policy makers, the disability community, and researchers over the past decade. Calls for greater policy and program accountability and effective planning, both within and outside of government, have fueled an interest in disability-related data. Policy issues on the forefront of the disability agenda, such as long-term services and employment, require relevant measures, accurate data, routinely repeated measures, sophisticated analysis, and both broad and well-targeted dissemination.

Changes in federal data collection activities are likely to be long-term efforts with significant political and resource considerations. Cost implications of developing new questions or expanding sample sizes are not to be ignored. The politics of negotiating new or replacement questions must be a consideration in carrying out any recommendations.

During the past several years, numerous conferences and workshops have been held to discuss the status of disability-data-related activities of the Federal Government, including data collection and statistical reporting of disability. The purpose of this report is to synthesize the recommendations of those groups and present action steps for implementing changes in federal data collection activities.

The following action steps address six areas of primary importance in disability statistics: orienting disability data collection activities to the new paradigm of thinking about disability, improving organizational structure, refining current data collection efforts, using existing data, developing new data collection instruments, and broadening dissemination.

ORIENTING DISABILITY DATA COLLECTION ACTIVITIES TO THE NEW PARADIGM OF THINKING ABOUT DISABILITY

With the enactment of the Americans with Disabilities Act (ADA) in 1990, a new paradigm of thinking about disability was firmly established in law and policy. Moving away from the medical model that usually forms the foundation of disability policy, this new paradigm offers a civil rights orientation that focuses on societal barriers to full participation rather than the functional impairments of the individual. The disability community has embraced ADA as its declaration of independence, one that articulates a vision of an accessible and equitable society. However, the vast majority of data collection activities of the Federal Government retain the medical bias and have not yet adopted the new paradigm. Examples of medical bias are found in questions about work in population-based surveys such as the Decennial Census and the Current Population Survey (CPS). Questions in those surveys focus on the individual's impairment and functional level but fail to identify barriers in society and the environment—such as discrimination and lack of accommodations in the workplace—that are potential obstacles to employment, assuming instead that the obstacles to employment reside solely with the individual as a result of the impairment itself.

Ideally, disability measures should also tell us about participation with and without accommodations. ADA recognizes the need for and emphasizes the use of accommodations to enable people with disabilities. Measuring the use of accommodations will not only indicate the gross level of need; it is also the best indicator of how well we are meeting ADA goals.

With the enactment of ADA, people with disabilities established themselves as a minority group with civil rights protections comparable to those available to other protected groups, such as ethnic and racial minorities, women, and the elderly. As a minority group, people with disabilities increasingly seek to have data about themselves that are comparable to data collected

about other protected groups. For example, through the CPS, the Bureau of Labor Statistics collects and disseminates data each month about the employment rate of other protected groups; such data are collected and disseminated only yearly about people with disabilities.

The following action steps are recommended to infuse the disability paradigm embodied in ADA into federal data collection activities.

1. Use ADA as the basis for the definition of disability in federal surveys.

ADA requires viewing disability as dynamic rather than static, as an interaction between an individual with an impairment and the environment rather than as a deficit of an individual. Definitions of disability need to be changed to reflect this orientation. In addition, questions about disability issues should be integrated into questions being asked of all respondents. For example, disability-related support needs could be included in a list of support needs in a question asked of all respondents, not just those who have identified themselves as having an impairment.

2. Operationalize the nation's goals for people with disabilities, as articulated in ADA, so that data can be collected about the extent to which society is moving toward reaching those goals.

ADA states that the nation's proper goals for people with disabilities are (1) equality of opportunity, (2) full participation, (3) independent living, and (4) economic self-sufficiency. Statistical measures should be developed for each of these goals. Data should be regularly collected to determine whether the nation is moving toward these goals. The government should dedicate resources to this effort.

3. Breakdowns by disability should be included in all federal data collections that collect data on gender and race/ethnicity.

Where data are collected, analyzed, and reported about other protected groups, this should also be collected, analyzed, and reported about people with disabilities. Such data activities are a

matter of both equity and good research. We recognize that there are unique issues involved in obtaining adequate samples of people with disabilities, but they should be resolvable with creative sampling techniques, larger samples, or both.

4. Methodological research on the survey definition of disability and its subtypes, on sampling issues, and on participation criteria should be ongoing.

Disability data collection is an evolving field. A formidable amount of work remains to improve the validity and accuracy of disability statistics. The constant methodological research being done in fields such as economics, physics, and medicine has proven invaluable for improving research results in those fields. Equal attention should be given to disability-related research to ensure that upcoming substantive research will be conducted appropriately.

5. Ensure that people with disabilities are integrally included in planning, developing, and carrying out disability-related data collection activities at all levels, from local to international.

People with disabilities should be a part of designing and refining data collection instruments, determining questions that will guide analysis, and developing dissemination strategies. Too often, data are generated that are irrelevant or unusable by people with disabilities. People with disabilities are often unaware of what is available. Inaccessible formats prevent meaningful use. People with disabilities should be provided financial support for their participation in the provision of data (e.g., responding to surveys and requests for information), the development of data activities, and the utilization of data. Information should be available in accessible formats in all phases of data collection activities.

IMPROVING ORGANIZATIONAL STRUCTURE

Numerous federal agencies and interagency entities are involved in disability data collection activities. Furthermore, most federal surveys operate with particular constituencies, both inside and outside of government, and in political environments. Coordination and collaboration are challenging but essential for effective data collection activities.

The following action steps are recommended to improve organizational structure.

6. Create a central coordination mechanism, such as a task force or committee, to effectively manage disability data efforts.

Because of the complexity of this task, the range of interest involved, and the need to make sound recommendations, this must be a high-ranking task force or committee that includes representation from the federal and state governments, the disability communities, research communities, and providers of services. Its charge should be to develop a plan within a delimited time span of about one year. This entity should work in conjunction with the Interagency Subcommittee on Disability Statistics.

7. Develop a mechanism for all federal agencies to exchange information regularly with the Department of Health and Human Services (HHS) Data Council, which reviews and clears all HHS surveys. The Interagency Subcommittee on Disability Statistics should be integrally involved in this effort.

REFINING CURRENT DATA COLLECTION EFFORTS

The Federal Government routinely carries out several large surveys. Appendix I includes a partial list of those surveys and a brief description of their purposes. Numerous conferences and reports have outlined recommendations for improving the disability questions in those surveys. A compilation of those recommendations follows each survey description in the appendix.

The following actions steps are recommended to refine current data collection efforts.

8. Revise census questions for the Year 2000 Census to reflect the ADA definition. Include such questions in the short form.

Numerous federal agencies have been working to revise the 1990 census questions on disability for use in the Year 2000 Census. Efforts should proceed until questions are developed that reflect the new paradigm of thinking about disability embodied in ADA. Questions about disability should be included on the short form only if sufficient space can be given or questions developed that will accurately capture the full disability community in the space available.

9. Continue active participation, including people with disabilities, in the revision of the International Classification of Impairments, Disabilities, and Handicaps (ICIDH), to promote an international standard and uniform coding schemes that include a measure of the disabled individual's participation in society and the accessibility of the environment.

Utilization of an internationally accepted classification system promotes meaningful international data exchange and analysis. During the past few years, the U.S. government has been actively involved in the ICIDH revision process, which includes the development of measures of societal participation and access. The ICIDH was revised in April 1997 into the ICIDH-2 beta version. The beta version is scheduled for review and approval by the World Health Organization's World Health Assembly in April 1999.

10. Expand the monthly Current Population Survey questionnaire to include questions on the employment of people with disabilities.

Currently the Bureau of Labor Statistics collects data about the employment of people with disabilities only once a year, in the March supplement. Data about the employment of other protected groups are collected and reported on a monthly basis. Including people with disabilities in this monthly collection and analysis would bring public attention to the problem of the high level of unemployment among people with disabilities. Questions used in the Current Population Survey should be reviewed to ensure that they are consistent with the new paradigm of disability and that they will accurately capture work information for people with disabilities.

11. Develop and refine a constellation of disability indicators that will comprise Goals 2010 for the forthcoming Healthy People 2010 effort.

12. Integrate data on people with disabilities into all existing or proposed data collection efforts being carried out through major government initiatives.

This action would include information-gathering efforts related to such programs as the school-to-work transition program, health care, and welfare reform to enable determination of the impact of these programs on people with disabilities. Surveys about topics such as crime and tourism should include questions about people with disabilities. A goal is to have at least one "global disability indicator" on every federal, state, and small-area survey funded by the Federal Government.

13. Ensure that the broadest range of people with disabilities (including children, those with hidden disabilities, and minorities with disabilities) are sampled.

To understand the unique aspects of all people with disabilities, it is critical that all groups be adequately sampled. Frequently, too few people with a particular disability or of a particular age or ethnicity are sampled to allow for statistically sound analysis.

USING EXISTING DATA

The following action steps are recommended to make better use of existing data.

14. Ensure extensive analysis of data from the disability supplement to the National Health Interview Survey.

15. Require coordination and linking of data with and across federal and state systems as a way of ensuring quality, accuracy, efficiency, and confidentiality of data.

There is currently a large amount of duplication among data collection efforts, as well as significant gaps in data collection. Improved coordination of efforts could eliminate duplication and identify gaps. Linkage of data sets would facilitate effective research into complex questions.

16. Evaluate data elements of state systems for data elements common to both federal and state data banks and identify minor modifications that could establish additional common data elements, including key demographic, disability, service and cost variables.

Many informational needs (such as characteristics of low-prevalence populations and outcome efforts) cannot be addressed via federal data efforts. Significant data on needs, programs, outcomes, and efficacy are found at state and local levels more often than at the federal level. The Federal Government should take the initiative to identify, synthesize, and make available the significant amount of data that exist at state and local levels. The government should examine new disability data collections funded by National Centers for Environmental Health to be used soon in 16 states on their Behavioral Risk Factors Surveillance System survey. It should ask state health departments for their experience in making state estimates and evaluate the State and Local Area Integrated Telephone Survey, the new National Center for Health Statistics (NCHS) National Health Interview Survey (NHIS) designed to greatly enhance state estimates. It should review recently published techniques for making small-area estimates (such as *Indirect Estimators in U.S. Federal Programs*, edited by W. L. Schiabile and published by

Springer-Verlag), and it should note the level of individual unit analysis currently permitted on NCHS public use tapes.

17. Backcode additional surveys to the ICIDH or ICIDH-2 beta version or both, to produce roughly comparable disability data now from data collected previously with no goal of being comparable to any national or international standard.

Apply algorithms used in the successful backcoding efforts of the Department of Education, the United Nations Statistical Division's DISTAT project, and the National Center for Medical Rehabilitation Research's Research Archive on Disability in the United States.

DEVELOPING NEW DATA COLLECTION INSTRUMENTS

The following action steps are recommended to develop new data collection instruments.

18. Establish focus groups on the emerging issues and needs of persons with disabilities in the topical areas of major surveys before data collection instruments are planned.

It is not enough to have people review completed surveys; key constituencies must also be involved in defining the purpose and research questions of a study. Guidelines in NIDRR's Participatory Action Research (PAR) Report should be followed.

19. Develop a framework for the collection of employment data on persons with disabilities that allows (1) description of the employment patterns of persons with disabilities and (2) assessment of individual characteristics and work environments that account for these patterns.

These data should allow for an analysis of how disability affects the ability to work. Data should be collected on functional limitations, duration of impairment, age of onset, and human capital. In addition, the work environment should be analyzed in terms of its impact on disability and work.

20. Use an extensive set of indicators that can be reported monthly or annually to determine the progress in the employment situations of people with disabilities.

A labor utilization framework goes beyond collecting data on unemployment; it also collects data on part-time work, income compensation, and the degree to which people are fully employed in the labor force with respect to their human capital characteristics. These types of measures would extend insight into the nature of work disability.

21. Design well-written questions to measure work disability that separate the notions of employment and disability.

Work limitations must be described in the data, not by inference, as a function of environmental barriers and accommodation, including transportation, along with individual impairment. Both the National Center for Health Statistics and the Bureau of Labor Statistics have cognitive laboratories that are experienced in question design and could help address this issue.

22. Government surveys should collect the following employment-related data for people with disabilities: age, gender, race, region, veteran status, use of assistive technology, use of accommodations, productivity measures with accommodations, workplace flexibility, characteristics of the employer and the job, promotions and training, social support, transportation, access to benefits (including pensions, health insurance, and leave), qualifications for employment (including education and literacy), condition and impairment data (including severity, change over time, and age of onset), labor force patterns, level of awareness of public programs, impact of health insurance, motivational factors, social supports for employment, family resources, income, and assets.

Some of these items will require the development of new survey questions or the redesign of existing questions to reflect the new disability paradigm and to ensure the accuracy of the results.

23. Develop questions to determine the extent to which people with disabilities have access to the services and supports they need, including assistive technology, long-term support services, accessible community-based housing, and rehabilitation services.

24. Develop questions about voter registration and participation by people with disabilities, and routinely monitor these activities.

25. Develop and pilot-test measures for household and living arrangement classifications that could be incorporated into the sample frame enumeration used in the census and other surveys.

26. Ensure that any new disability questions reflect variations in ethnic cultural understanding of disability.

BROADENING DISSEMINATION

The following action steps are recommended to broaden dissemination.

27. Ensure that data and data analyses are disseminated in alternative formats and that they are accessible to people with all disabilities.

Formats such as Braille, large print, and computer disks will enable blind and visually impaired people to participate in all phases of disability research. Particular attention should be given to presentation of quantitative data commonly formatted in tables, graphs, and so on. Information should be formatted in a manner suitable for screen readers and other devices used by people with disabilities.

Access issues also apply for people with impairments that do not involve reading print. Methods needed to ensure everyone's participation in research depend on the specific research techniques used for most of the sample; for example, a telephone survey needs to accommodate direct participation by people with hearing and speech impairments.

To put teeth into recommendations concerning accessible materials, grants and contracts should be required to show what time and budget allocations will be made to accomplish the goal; peer review and agency review criteria should be established.

28. Federal agencies should develop requirements for dissemination of data and data analyses so they are widely available to the disability community, researchers, and other interested parties.

Federal agencies could require contractors and grantees, as a part of an award stipulation, to produce an ASCII database of raw data, a file of data definitions, and files of relevant data and study documentation (properly cleaned, formatted, and disidentified) for the sponsoring government agency at the end of the project period. The agency could then determine whether to

directly redistribute the data and documentation for secondary statistical analysis and educational purposes or to release the files to another organization for public access.

Appendix I

Major Surveys

American Housing Survey

The American Housing Survey (AHS) is conducted every other year by the American Housing Survey Branch of the Bureau of the Census. In 1995, the sample consisted of approximately 61,000 units. The sample areas, called primary sampling units, are stratified by region and urban/rural location. Both national estimates and estimates of selected metropolitan areas are available. Housing units form the sampling unit. An important feature of these surveys is that generally the same housing units remain in the sample year after year, and it is the housing unit rather than its occupants that is followed.

Recommendations for improving the American Housing Survey

- Improve the health and disability status section.
- Add a section to the instrument to obtain information on supportive services in special units.
- Develop a subsample of specialized housing units to permit the national profiling of trends in these settings.
- Structure the questionnaire and code the results to ICIDH-2.

National Health Interview Survey and Disability Supplement

The National Health Interview Survey (NHIS) is a continuous national survey sponsored by the National Center for Health Statistics. It provides data on acute conditions, limitations of activities, injuries, occupational disability, physician and dental visits, and selected chronic conditions. It also provides standard demographic information and some housing data. In

1994-95, a supplemental survey on disability was conducted to obtain additional information on the living arrangements and caregiver resources of this population. The survey instrument for the supplement includes questions on activities of daily living (ADL) and instrumental activities of daily living (IADL), mental retardation and developmental disabilities; physical, emotional, and cognitive impairments; transportation; employment barriers; home access and accommodation; and use of services.

Recommendations for improving the National Health Interview Survey and Disability

Supplement

- Implement a regular schedule for fielding the disability supplement.
- Add a more complete housing component, perhaps using the American Housing Survey format for categorizing special places housing within the disability supplement.
- Extend the quality-of-care questions to all ages among the disability group. (Presently, many of the quality-of-care items apply to the age 70+ population only.)
- Structure the questionnaire and code the results to ICIDH-2.

Decennial Census of Population and Housing

The Decennial Census encompasses the entire U.S. population. It provides data accumulated at the census tract level on household demographics, income by source, labor force participation, occupation, and type of dwelling. The number and relationships of persons in each household are also compiled. Included among the many tabulations and tape files is a summary statistics file representing a 100 percent count of persons in group quarters. The group quarters category includes persons in institutions and noninstitutions.

Recommendations for improving the Decennial Census of Population and Housing

- The most practical change would be to clarify the enumeration process for the multitude of specialized living arrangements and to create data files and tabulations that are specific to the settings.
- The housing or living arrangements categories should be consistent with those in the American Housing Survey. The Bureau of Census conducts the AHS, the NHIS, and the Decennial and Current Population surveys, reducing the barrier to the creation of common definitions and cross-identification.
- Consider adding questions applicable to specialized living settings that describe the physical and staff characteristics of facilities, as well as the services provided.
- Structure the questionnaire and code the results to ICIDH-2.

Medicare Current Beneficiary Survey

The Medicare Current Beneficiary Survey (MCBS) is sponsored by the Health Care Financing Administration as an ongoing, multipurpose survey conducted among a probability sample of Medicare beneficiaries. Also collected are data on health conditions, functional status, health care utilization, and demographics, including income and vital statistics. To date, there has been only one survey round in which a supplementary interview was conducted with a particular set of survey recipients; in this case those receiving home health care.

Recommendations for improving the Medicare Current Beneficiary Survey

- The addition of a more detailed housing classification would enhance the utility of MCBS for tracking supportive housing arrangements.
- The ability to organize living arrangement information by the health and functional status of household members would be useful in differentiating licensed from unlicensed supportive housing arrangements.

- Consider periodic supplemental surveys of specialized housing as a means of expanding knowledge of the population living in such settings.
- Data analysis should recognize that the sample is restricted to persons covered by Medicare and is not necessarily representative of the disability community as a whole.
- Structure the questionnaire and code the results to ICIDH-2.

Social Security New Beneficiary Survey

This survey, sponsored by the Social Security Administration, provides longitudinal data on disability and aging of new beneficiaries under Title 11 (workers with disabilities). Personal interviews are conducted with a random sample of noninstitutionalized beneficiaries and their spouses. The first wave was collected in 1982, and the second wave was conducted in 1992. Data collected include demographics, employment and income, health conditions that limit ability to do work, and limitations of activities (ADL and IADL). There are also data on long-term care in residential facilities.

Recommendations for improving the Social Security New Beneficiary Survey

- The housing, living arrangements, and services section of the instrument should be brought into alignment with whatever changes are made in the Medicare Current Beneficiary Survey.
- Like the MCBS, the Social Security Beneficiary Survey is directed only at a specific service population. Therefore, the problem of excluded individuals cannot be easily addressed.
- Structure the questionnaire and code the results to ICIDH-2.

Survey of Income and Program Participation (SIPP)

SIPP is a panel survey of the economic conditions of people in the United States. It is designed to provide detailed information about income distribution and about federal and state income transfer and service programs. It also provides information about limiting conditions among respondents 15 years and older. Disability data for children ages 0 through 14 are obtained from their parents. SIPP contains information on economic and social variables of persons with disabilities that are not usually included in health surveys that ask about disability.

Recommendations for improving the Survey of Income and Program Participation

- Include better data on impairment in SIPP, perhaps by using International Classification of Diseases codes, so that the specific impairment can be more accurately linked to the employment outcome experienced by the person in a workplace.
- Use SIPP as a complementary data source to the Current Population Survey (CPS) to describe the employment patterns of persons with work disabilities. The CPS is used to provide the monthly unemployment rate for persons in the United States. Extending that set of indicators would allow reporting not only on the unemployment rate but also on the levels of full employment among persons with and without disabilities.
- Structure the questionnaire and code the results to ICDH-2.

Appendix II

Mission of the National Council on Disability

OVERVIEW AND PURPOSE

NCD is an independent federal agency led by 15 members appointed by the President of the United States and confirmed by the U.S. Senate.

The overall purpose of NCD is to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities, regardless of the nature or severity of the disability; and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society.

SPECIFIC DUTIES

The current statutory mandate of NCD includes the following:

- ☐ Reviewing and evaluating, on a continuing basis, policies, programs, practices, and procedures concerning individuals with disabilities conducted or assisted by federal departments and agencies, including programs established or assisted under the Rehabilitation Act of 1973, as amended, or under the Developmental Disabilities Assistance and Bill of Rights Act; as well as all statutes and regulations pertaining to federal programs that assist such individuals with disabilities, in order to assess the effectiveness of such policies, programs, practices, procedures, statutes, and regulations in meeting the needs of individuals with disabilities.

- ☐ Reviewing and evaluating, on a continuing basis, new and emerging disability policy issues affecting individuals with disabilities at the federal, state, and local levels and in the private sector, including the need for and coordination of adult services, access to personal assistance services, school reform efforts and the impact of such efforts on

individuals with disabilities, access to health care, and policies that operate as disincentives for individuals to seek and retain employment.

- ☐ Making recommendations to the President, the Congress, the Secretary of Education, the Director of the National Institute on Disability and Rehabilitation Research, and other officials of federal agencies regarding ways to better promote equal opportunity, economic self-sufficiency, independent living, and inclusion and integration into all aspects of society for Americans with disabilities.
- ☐ Providing the Congress, on a continuing basis, with advice, recommendations, legislative proposals, and any additional information that the Council or the Congress deems appropriate.
- ☐ Gathering information about the implementation, effectiveness, and impact of the Americans with Disabilities Act of 1990 (42 U.S.C. 12101 et seq.).
- ☐ Advising the President, the Congress, the Commissioner of the Rehabilitation Services Administration, the Assistant Secretary for Special Education and Rehabilitative Services within the Department of Education, and the Director of the National Institute on Disability and Rehabilitation Research on the development of the programs to be carried out under the Rehabilitation Act of 1973, as amended.
- ☐ Providing advice to the Commissioner with respect to the policies and conduct of the Rehabilitation Services Administration.
- ☐ Making recommendations to the Director of the National Institute on Disability and Rehabilitation Research on ways to improve research, services, administration, and the collection, dissemination, and implementation of research findings affecting persons with disabilities.

- ☐ Providing advice regarding priorities for the activities of the Interagency Disability Coordinating Council and reviewing the recommendations of this Council for legislative and administrative changes to ensure that such recommendations are consistent with the purposes of the Council to promote the full integration, independence, and productivity of individuals with disabilities.
- ☐ Preparing and submitting to the President and the Congress an annual report titled *National Disability Policy: A Progress Report*.
- ☐ Preparing and submitting to the President and Congress an annual report containing a summary of the activities and accomplishments of the Council.

INTERNATIONAL

In 1995, NCD was designated by the Department of State to be the official contact point with the U.S. government for disability issues. Specifically, NCD interacts with the special rapporteur of United Nations Commission for Social Development on disability matters.

CONSUMERS SERVED AND CURRENT ACTIVITIES

While many government agencies deal with issues and programs affecting people with disabilities, NCD is the only federal agency charged with addressing, analyzing, and making recommendations on issues of public policy that affect people with disabilities regardless of age, disability type, perceived employment potential, economic need, specific functional ability, status as a veteran, or other individual circumstance. NCD recognizes its unique opportunity to facilitate independent living, community integration, and employment opportunities for people with disabilities by ensuring an informed and coordinated approach to addressing the concerns of persons with disabilities and eliminating barriers to their active participation in community and family life.

NCD plays a major role in developing disability policy in America. In fact, it was NCD that originally proposed what eventually became ADA. NCD's present list of key issues includes

improving personal assistance services, promoting health care reform, including students with disabilities in high-quality programs in typical neighborhood schools, promoting equal employment and community housing opportunities, monitoring the implementation of ADA, improving assistive technology, and ensuring that persons with disabilities who are members of minority groups fully participate in society.

STATUTORY HISTORY

NCD was initially established in 1978 as an advisory board within the Department of Education (Public Law 95-602). The Rehabilitation Act Amendments of 1984 (Public Law 98-221) transformed NCD into an independent agency.

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