

... working for full equality for Iowans with disabilities

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Frances Brunkan
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Systemic Change

Empowerment

A PLAN FOR IOWA

1995-1997

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August 15, 1994

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CITIZENS' AIDE/OMBUDSMAN

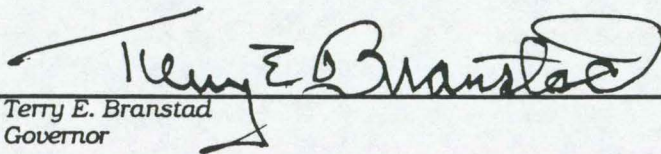
**The Developmental Disabilities
Three Year State Plan
for Federal Fiscal Years 1995, 1996, 1997**

October 1, 1994 - September 30, 1997

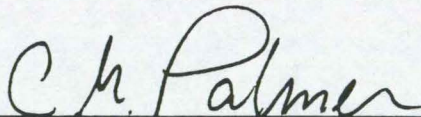
STATE OF IOWA

Prepared and submitted by:

***The Iowa Governor's Planning Council for Developmental Disabilities (In consultation
with the Designated State Agency)***



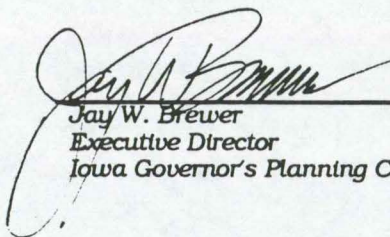
Terry E. Branstad
Governor



Charles M. Palmer
Director
Department of Human Services (Designated State Agency)

Keith E Ruff

Keith Ruff
Chair
Iowa Governor's Planning Council for Developmental Disabilities



Jay W. Brewer
Executive Director
Iowa Governor's Planning Council for Developmental Disabilities

August 15, 1994

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INTRODUCTION

The Iowa Governor's Planning Council for Developmental Disabilities is created in response to a federal law, the Developmental Disabilities Assistance and Bill of Rights Act. The purpose of the law is to assure that people with developmental disabilities and their families help design and have access to necessary services, supports, and other assistance. The Council is to promote, through systemic change, capacity building and advocacy, a coordinated system of culturally competent services and supports that provide opportunities for people with developmental disabilities to be independent, productive, integrated, and included in their communities. This state plan outlines how the Iowa Council will carry out these responsibilities.

Definition of Developmental Disability

Developmental disability means a severe, chronic disability of an individual 5 years of age or older that:

- *is attributable to a mental or physical impairment or combination of mental and physical impairments;*
- *is manifested before the individual attains age 22;*
- *is likely to continue indefinitely;*
- *results in substantial functional limitations in three or more of the following areas of major life activities;*
 - *self care*
 - *receptive and expressive language*
 - *learning*
 - *mobility*
 - *self-direction*
 - *capacity for independent living*
 - *economic self-sufficiency*
- *and reflect the individual's need for a combination and sequence of special, interdisciplinary, or generic services, supports, or other assistance that are of lifelong or extended duration and are individually planned and coordinated; except that such term, when applied to infants and young children means individuals from birth to age 5, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided.*

Public Law 103-230
Developmental Disabilities Assistance
and Bill of Rights Act
1994

Iowa Governor's Planning Council for Developmental Disabilities

MISSION STATEMENT

The Iowa Governor's Planning Council for Developmental Disabilities gathers information, develops plans and advocates supports and systems that empower all people with developmental disabilities to exercise their right, along with all Iowans, to fully participate as independent, productive and integrated members of their community.

Adopted April 15, 1993

Because, for all of us, disability is a natural part of the human experience and in no way diminishes the right of individuals with developmental disabilities to live independently, enjoy self-determination, make choices, contribute to society, and experience full integration and inclusion in the economic, political, social, cultural and educational mainstream of American society, the

Council adopts the following Guiding Principles:

- 1. Individuals with developmental disabilities, including those with the most severe developmental disabilities, are capable of achieving independence, productivity, integration and inclusion into the community, and the provision of supports, services and other assistance can improve their ability to achieve independence, productivity, integration and inclusion;*
- 2. Individuals with developmental disabilities, and their families when appropriate, should be the primary decision-makers regarding the supports and services they need, and play decision-making roles in the policies and programs which affect their lives (children and adults who are dependent on others need to be encouraged to make as many decisions about their lives as possible);*
- 3. Individuals with developmental disabilities and their families have competencies, capabilities and personal goals that should be recognized, supported and encouraged;*
- 4. Individuals with developmental disabilities and their families should receive supports, services and other assistance provided in a culturally competent manner that demonstrates respect for individual dignity, personal preferences, and cultural diversity;*
- 5. Individuals with developmental disabilities and their families enrich communities in which they live when they have full, active participation, and their contributions should be valued; and*
- 6. Individuals with developmental disabilities and their families should have opportunities and the necessary support to be included in community life, have interdependent relationships, live in homes and communities, and make contributions to the life of their communities and State.*

Adopted April 21, 1994

State Context

There is evidence across state departments of a movement toward in-home and family centered services, the importance of integration as a goal for services, and a growing recognition of the importance for people with disabilities and family members to be involved in making decisions about their own services. At the same time, policy makers, state agencies, providers, advocates and people with disabilities and their families all agree that significant changes are needed in Iowa's system of services and support, particularly for adults with disabilities. Problems range from how the system is organized and funded to the types of services that are available. Numerous studies completed over the past ten years have provided insight into the problems, as well as options for solving the problems. However, agreement on the solutions has continued to elude us all.

In recognition of the importance of developing a consensus on an agenda for change, in 1992 the legislature established the MH/MR/DD/BI (Mental Illness, Mental Retardation, Developmental Disabilities, and Brain Injury) Service Delivery System Restructuring Task Force. The Task Force brought together representatives of 25 constituent groups including consumers, advocates, state and county officials, services providers, business and industry, farm interests, and legislators. DD Council Chair, Keith Ruff, represented the Council on the Task Force. In January of 1994 the Task Force, concluding that "the current system is flawed beyond adjustment or modification", issued the following recommendations:

1. Revise services to be more focused upon the needs of consumers.
2. Move to equity of service availability around the state and to a core set of basic services.
3. Increase the leadership role of the state in service delivery and funding.
4. Maximize current financial resources in the near term through the use of federal funds and redirect funds away from institutional services to community-based services.
5. Restructure the system over the five-year period of FY 1994-1995 through FY 1998-1999 by expanding the use of the regional planning councils, implementing a revised role for the state, and capping county expenditures.

These recommendations reflect that Iowa has relied on a decentralized, or county-based service system, funded primarily through local property taxes. This has resulted in unequal access, based on the county in which a person lives. Many counties have reached their limits on taxing capacity. Budget problems, in general, have been magnified by a state mandated local property tax limitation on counties that has been in effect for the past two years and was extended through 1996 during this past legislative session. This has resulted in services being reduced and people being denied services in several counties.

Unfortunately, consensus was not achieved between the state and counties on two issues essential for system restructuring - who makes decisions about the system and who pays. In an attempt to deal with these unresolved issues, during the 1994 legislative session the Iowa Legislature passed and Governor Branstad signed, House File 2430. Through this bill an initial step, albeit small one, is taken by the state in assuming more responsibility for funding services. Additionally, a structure is created - a management team - for joint decision making on issues such as funding. Creating additional incentive for the state and counties to agree on solutions to problems, the

bill includes the extension on limiting the counties ability to raise property taxes, an item that has been high on the governor's agenda. However, at the same time the bill provides that this limitation is lifted if the state does not carry through with its commitment for appropriating funds for some services.

The interest in property taxes has helped to get disability service issues higher on the political agenda, an opportunity the Council recognizes. To further pressure for change the Council has focused on capacity building in Iowa's consumer and family networks. Two Council projects, the Iowa Family Support Initiative and the Systems Change Project, played a critical role in advocating for the passage of state legislation which promotes the independence, productivity, and inclusion of people with disabilities, specifically:

- House File 2302, a bill which creates two separate programs: personal assistance services and comprehensive family support (though actual implementation is contingent on yet to be appropriated funding), and
- House File 2403, which relates to targeted small business loans and assistance for entrepreneurs with disabilities.

Resources reviewed to examine the extent to which services and supports are needed and available to individuals with developmental disabilities and their families are listed in the appendix.

The Iowa DD Council Response to the State Context

The Council realizes that sometimes the best way to encourage others to change is to change itself. To be most effective, the Council also had to look at how it did business, how it was structured, how it operated, what its principles were.

The Council is slowly making headway in learning how to be sensitive to cultural diversity and weave that delicate and important thread throughout Council actions. It is working to incorporate cultural sensitivity into everything it does rather than develop a separate program. It has to develop strategies to become reflective of the state's population. The Council's membership consists of 11.5% minorities. While this representation overall exceeds the corresponding populations in Iowa, the Council realizes that in terms of programs, projects and involvement of those not of the majority culture, the Council has significant work to do. DD Council members and staff have begun a process of examining issues of cultural diversity and discovering approaches, problems and solutions related to our individual and common needs. DD Council members and staff are actively seeking opportunities to broaden our understanding, and will attend a statewide conference on diversity early in the fiscal year. Staff and Council members expect to apply their new perspectives to all of the Council's work in order to better address the needs of all Iowans with disabilities. As one early step, the Council has incorporated criteria addressing cultural sensitivity and diversity into its evaluation of applications for all projects.

In order to comply more fully with the federal law and provide more opportunities for new individuals to serve, the Council changed its rules to provide for regular rotation of Council members. This has meant the loss of some very fine, dedicated Council members, but it has also made it possible for new members to bring new ideas to the Council. More individuals with disabilities were appointed to the Council and more individuals with disabilities and family members now serve on the Executive Committee of the Council. Planning methods have changed to include the entire Council in joint planning so everyone would have ownership and a unity of purpose.

The Council developed and adopted an expanded conflict of interest policy to ensure the Council is accountable to the public and its resources are available in a fair manner to all. It has tried to break out of the mold of how it has done things in the past and try to see what it needs. It has tried to develop activities in such a way as to more directly involve individuals with disabilities. It is looking at training for Council members as individuals and the Council as a whole.

The Council has decided that it must model the behavior it wants others to adopt placing individuals with disabilities at the forefront of system change activities. The Council's System Change Project is managed by individuals with disabilities. The Council's project, IFSI (Iowa Family Support Initiative) is managed by parents of children with disabilities. Individuals with disabilities are the leaders of the Council and its activities.

Issues People with Disabilities see as Important

The DD Council gathered input from individuals with disabilities and parents of small children with disabilities, participants of its projects, and readers of its publication IDD NEWS. The process identified the following issues that significantly affect Iowans with developmental disabilities.

1. Empowerment: Individuals with disabilities and their families want to affect the choices available to them and to have the power to make informed choices about their own lives.
2. Funding System and Policy Changes: The current state funding system and related public policies do not maximize opportunities and choices for people with developmental disabilities to be independent, productive, and included members of the community.
3. Aging of Elderly Persons with Developmental Disabilities: Often, the problems that older individuals with developmental disabilities face are compounded as a result of ill-conceived services, uncoordinated efforts and misinformation or a general lack of planning. Elders with disabilities continue to need to have options and the supports necessary to exercise their options.
4. Independent Living Movement: Individuals with disabilities need avenues to speak, advocate, and to do for themselves. Many are demanding cross-disability, non-residential, consumer controlled, and consumer run services and supports.
5. Povertization of People with Developmental Disabilities - Including Those Employed: Individuals with developmental disabilities, often including those who work, lack sufficient economic resources to live comfortably, and their disability often causes additional expenses.
6. Family Support: We need a system of services and supports that prioritizes family support and services that are "family-centered", family driven, convenient, flexible and individualized. We need to provide the supports it takes to help keep children with disabilities with their families in safe, nurturing, and healthy families.
7. Home Choice and Control: Individuals with developmental disabilities should have the opportunity to own their own home if they wish and to have control over the place in which they live.
8. Transportation: There is limited inter and intra-community mobility of individuals with disabilities.
9. Use of Technology by Persons with Developmental Disabilities: Individuals with disabilities have limited access to assistive technology.
10. Access to Services in Rural Areas: Where you live in Iowa is a strong determinant of the services available. Funding by county leads to inconsistent service availability and quality.
11. Case Management: There is no statewide comprehensive system of case management currently in Iowa for individuals with developmental disabilities. Individuals with disabilities are interested in an empowering service coordination/brokering approach that is often lacking in current "case management" services.

12. Child Care: Families with children with disabilities do not have the same access to child care as families with children without disabilities.
13. Denial of Access to Health Care to Persons with Disabilities: Providers are not participating in the Medicaid program because of low reimbursement levels and many people with disabilities are having problems accessing the health care they need.
14. Education: The vision of an integrated, appropriate education for all students with disabilities is not fully realized even after 20 years of rules and regulations.
15. Employment: The vision that every person can work in the community in a career of their choice with the appropriate types and amounts of support could be realized through its adoption by family members, employers, providers of employment services, funders and policy makers.
16. Language Clarity in Regulatory and Legislative Policy: People deserve legislative and executive branch rules and regulations written in clear and understandable language.
17. Personal Assistance Services: Personal assistance services are not readily accessible to 56,500 Iowans who need them in order to live, work, recreate independently. There are problems in the availability of services and in funding.
18. Post Secondary Education: Opportunities for employment are directly proportional to education and training; individuals with disabilities should have equal access to post secondary educational opportunities.
19. Prevention: There is a great need to enable people to prevent developmental disabilities with existing knowledge and to prevent the abuse of people with developmental disabilities which might lead to a secondary disability.
20. SSI and Children with Developmental Disabilities: Inequity in the application of the SSI rules and regulations seem to discriminate against children. Statistics show that a high percentage of Iowa children with disabilities who should be eligible for SSI are not receiving it.
21. Information/Services and Referral System: People need direct access to information and referral so they can make decisions on their own.
22. Collaboration, Coalitions and Alliances with Organizations and Groups: Disability advocates are not working most effectively with other advocacy groups to get out common messages and to unite to affect systems change.
23. Active Involvement of People with Disabilities in Determining the Services and Supports Needed: People need to have a choice in the services they receive and opportunity in determining the priority of services offered.

Iowa Council's Priority Issues

Because of significant problems in Iowa caused by how the system is structured and funded, and by the number of unmet needs in Iowa, the DD Council had to decide how to be most effective in bringing about change. During the past two years, the Council has examined its role as a potential change agent. The Council must become better known as a change agent. It has decided to become more assertive in influencing state public policy regarding disability issues.

This was a difficult task because the Council realized that if it was to be effective, it had to narrow its focus. This meant it could not address all of the issues affecting individuals with disabilities. However, the Council is excited to have narrowed the above 23 issues to the two priority areas listed below. These issues will guide what the Council will do in the next three years.

1. Empowerment: People with disabilities and their families want to affect the choices available to them and to have the power to make informed choices about their own lives.
2. Funding System and Policy Changes: The current funding system and related public policies do not maximize opportunities and choices for people with developmental disabilities to be independent, productive, and included members of the community.

The goals and objectives that follow are the DD Council's planned response to its priorities and the challenges of the state. In order to assure each of these objectives is adequately addressed, the Council has established a process for evaluating objectives on an annual basis. Prior to writing the Council's annual report, staff will present to the Council a summary of progress made toward each objective, with anticipated next steps. The Council will review and comment and will use this tool to re-examine and re-direct its efforts each year.

CHARTING THE COURSE FOR SYSTEMIC CHANGE AND EMPOWERMENT

Reaching this goal will require actions by individuals with disabilities and their families and change in public policy and funding for the system of supports and services in Iowa.

DD Council's Long Term Goal for Iowa:

Individuals with developmental disabilities will exercise the same rights and responsibilities as all other citizens including:

- Affecting the choices that are available to them
- Making their own decisions, based on full access to information
- Living and working in their own homes and communities and contributing to their homes, neighborhoods, communities and to society in general.

Individual Actions: Empowerment Outcomes

Individuals with developmental disabilities and their families will:

- exercise their rights and responsibilities through choice and control over their lives;
- affect policy and help determine the types and priorities for supports and services;
- use their power (information, knowledge, experiences, numbers, skills, and support) to make changes; and
- be included in society and at their community level and recognized as leaders.

Systemic Change: Funding for Services and Public Policy Outcomes

The system of services and supports will include the following:

- A legislatively adopted set of values and principles will guide all supports and services in the state for individuals with disabilities and family members, and require:
 - services in individuals' own homes, community and on the job be the priority for receiving funds and that a reimbursement system gives providers incentives to make them available;
 - the type of disability and place of residence do not limit supports and services individuals receive;
 - policies and procedures guarantee choice over what services they receive, including how, where, and from whom they receive it;
 - supports and services are efficient and provide no more than what individuals want.

- Individuals who use services are involved in planning, implementing and determining policy, and evaluating services.
- There is an increase in state funding so that the cost of the service system not paid by the federal government is shared equally by the state and counties, along with increased state leadership.

Designated Federal Priority Areas for State Plan Objectives

The DD Council has chosen the following two designated federal priority areas:

Employment

Activities in this priority area are those that increase the independence, productivity, integration and inclusion into the community of individuals with developmental disabilities in work settings.

System Coordination and Community Education

Activities within this priority area are those that a) eliminate barriers to access and eligibility for services, supports, and other assistance; b) enhance systems design, redesign, and integration, including the encouragement of the creation of local service coordination and information and referral statewide systems; c) enhance individual, family, and citizen participation and involvement; and d) develop and support coalitions and individuals through training in self-advocacy, citizen leadership skills and assisting in educating policy makers.

DD Council Objectives for FFY 1995-1997 (October 1, 1994 - September 30, 1997)

- A. An information system will be readily available to people with disabilities and families.
- B. Individuals with disabilities will be educated about their rights, opportunities, and possibilities, including economic independence through employment.
- C. Supports that are necessary for participation in decision making and policy development will be available to individuals with disabilities and families.
- D. Individuals with disabilities will be organized to change the system.
- E. Individuals with disabilities will be trained and take leadership positions in advocacy and system change activities.
- F. Children with disabilities will be included in existing children's community programs.
- G. Relevant, usable information will be made available to systems planners, funders, legislators, county supervisors, and agency representatives to convince them to appropriate funds and implement supports and services consistent with the principles and vision of this plan.

H. Advocacy by the Council, in cooperation with others, will result in the legislative and executive branches adopting and implementing the Restructuring Task Force's plan which outlines:

- values and principles;
- what services will be available, how they will be available and how they will be paid;
- a service system structure that is consistent with the vision adopted by the Council

I. Alliances will be formed between individuals with disabilities and policy makers so they can communicate directly. Alliances of disability organizations will be formed so policy makers hear a unified message.

J. Individuals and families will be supported with:

- information on the positions of candidates on disability issues;
- information on the importance of voting and how to vote;
- assistance in increasing their numbers serving on planning or policy boards;
- financial resources, personal assistance services, family support or other help so they can be directly involved in advocating for changes in the system of services and supports;
- information on how the current funding and service system operates, on policy options and debates, and actions for change being contemplated by public officials.

K. The general public will be educated that:

- current laws, services and funding priorities result in discrimination and segregation of individuals with disabilities;
- individuals with disabilities can and do take responsibility for their own lives and contribute to their communities;
- individuals with disabilities offer benefits as neighbors and co-workers.

DD Council Strategies for FFY 1995-1997 (October 1, 1994 - September 30, 1997)*

* *Some of the following strategies are cross-cutting and relate to more than one of the previously listed objectives.*

1. Advocate for and provide supports and technical assistance that help establish programs and approaches that assist individuals with disabilities to be economically self-sufficient through employment and other opportunities. (Staff involvement in a state-wide supported employment system change project; staff assistance in expanding Iowa's targeted small business program to people with disabilities. No direct federal ADD funds.)
2. Assist individuals with disabilities through technical assistance and support to become self-employed entrepreneurs whose business is to develop, write and monitor PASS (Plan for Self-Support) and IRWE (Income Related Work Expense)

regarding Social Security work incentives for individuals with disabilities. (\$25,000, first year, \$15,000, second year beginning January 1, 1995)

3. Provide current information on disability issues, supports and contemporary services to people with disabilities, their friends and families, providers and others through the Clearinghouse library and a quarterly newsletter, "The Review". (Collaborate with the University Affiliated Program for the Clearinghouse and newsletter, funding at a level of \$48,000 each year.)
4. Fund a targeted, intensive two-year marketing effort to increase awareness of COMPASS among individuals with disabilities, family members, service providers, rehabilitation facilities and other professionals. (Contract to COMPASS, \$30,000 per year, beginning October 1, 1994)
5. Remain a partner in funding and overseeing the operation of Iowa COMPASS with the University Affiliated Program, the Department of Education, Divisions of Special Education and Vocational Rehabilitation, the Department of Human Services and Child Health Specialty Clinics and advocate for funding with state agencies and the legislature. (Staff plus contract of 10% of COMPASS' operating budget each year, up to a maximum of \$30,000.)
6. Provide Partners in Policymaking leadership training for 30-35 people each year for three years and ongoing support to the 125-plus Partners grads for their ongoing involvement in systems advocacy activities. (\$100,000 per year under contract beginning October 1, 1994 and staff technical assistance to the project for the training; \$25,000 to fund mini-grants to support ongoing advocacy activities by Partners and to fund an annual Partners conference)
7. Provide advanced leadership training and technical support to graduates of Partners training, other advocacy and leadership training, and other individuals with disabilities and family members who are leaders in Iowa in system advocacy each year for three years. (\$40,000 per year under contract beginning October 1, 1994)
8. Evaluate the feasibility of and implement a pilot project to assist people with disabilities and families to apply the information they receive from Iowa COMPASS to their own circumstances to accomplish personal goals and meet their needs. (Up to \$100,000 per year under contract for up to three years; staff technical assistance in planning and implementing the pilot.)
9. Analyze the effectiveness of current disability rights educational activities in Iowa and use the results to determine what and how activities should change. (\$10,000 for a six month contract; Council and staff to use the results.)
10. Design, pilot and evaluate the effectiveness of providing information as the means to persuade and positively influence the inclusion of children with disabilities in community programs. (Up to \$75,000 per year under contract beginning October 1, 1994 for two years)
11. Plan for, design, coordinate and implement public education activities related to the Council's priorities, objectives, and contracted activities. (Council, council staff, and a contractor. (\$36,000 the first year and up to \$50,000 each of the following two years)

12. Assess how awareness efforts can promote positive perceptions of people with disabilities by the public to build support for public policies and funding of services that promote independence, productivity and inclusion. (One year contract for \$30,000; staff planners to assist the Council in using the results)
 13. Establish an advocacy network or organization of people with disabilities and others to accomplish an agenda of changes to the system that people with disabilities want. (\$125,000 per year for three years under contract; staff technical assistance)
 14. Develop cross-disability coalitions around specific policy and funding changes, develop consensus for change, and work with these groups to advocate for the changes. (Staff; \$7,500 for individual contracts for technical assistance, group facilitation, etc.)
 15. Analyze policy trends and position the Council to address significant emerging policy or funding issues through planning and advocacy. (Staff, Council and technical assistance contractor noted in strategy 17 below.)
 16. Adopt a 1994-96 prioritized, public policy agenda and advocate for funding, service or policy changes needed from the legislature, executive branch agencies, county government, and providers to implement the agenda. (Staff and Council)
 17. Provide information and data to support the Council's public policy positions. (Staff; technical assistance contractor and research projects totaling up to \$100,000 per year)
- * *Strategies are designed to be implemented over the entire 1994-1996 state plan period to accomplish the Council's objectives, unless otherwise noted.*

Role of the Developmental Disabilities Planning Council

In carrying out its mission within Iowa state government, the Council fulfills its role with a commitment to empowerment of people with developmental disabilities. The Council believes that effective advocacy and system change can only occur when people with developmental disabilities and their families lead the change process. Through information, training, and support for involvement in the development of policy that affect their lives, the Council strives to fulfill its planning and advocacy role in a manner that maximizes the personal power of people with developmental disabilities. The Iowa Governor's Planning Council for Developmental Disabilities was established in Iowa by Executive Order in 1976. The Council is composed of 26 members with appointments made by the governor for three-year terms.

DD Council Staff

- **Executive Director** - Jay W. Brewer, June 1992, has nearly 30 years of experience working with individuals with disabilities, including state vocational rehabilitation, long term care facility, private provider of services, education, state office for mental health, mental retardation, developmental disabilities and developer of rehabilitation modifications. He has been an advocate for individuals with disabilities from within and outside the state system. He has a Masters degree in administration.
- **Secretary** - Debbie Jones, September 1987, has held a variety of clerical and secretarial positions both in private and public agencies. She provides support to the Council and Council staff and has responsibility for fiscal and contract records in addition to normal clerical functions.
- **Public Policy Manager** - Julie Dettmann, March 1987, is responsible for the Council's public policy activities. She also manages the System Change Project and other contracts. Julie has 15 years of experience in the public sector and 3 years in the private sector in a variety of roles in adult, children and family services, health care and corrections. She has a Masters of public administration and a B.S. in Sociology.
- **Project Manager** - Ken Tigges, August 1990, has specialized in family support at the state and national level and personal assistance. He has managed the Partners in Policymaking contract for the last 4 years. He is a resource in children's issues. Ken has 12 years public sector and 3 years private sector experience involving services for people with disabilities. His background includes case management, foster care and family centered services in the field. Ken has a B.A. in Social Work.
- **Fiscal Manager** - Patricia Winters, July 1993, is the Council's fiscal officer in addition to her work with some contractors. Her experience includes work with various public and private agencies in Iowa, Washington, D.C., and overseas. She has worked as a claims examiner, coordinator of services, management analyst and grants officer. Pat has a B.A. in Sociology.

1995 - 1997 State Planning Council

The Developmental Disabilities Council is responsible for the development, implementation and monitoring of the state plan for developmental disabilities. Leadership for these efforts during the next year will be provided by:

Executive Committee

Keith Ruff, Chair
601 S. Gilbert, #611
Iowa City, IA 52240

Linda Haley, Vice Chair
Frances Brunkan, Member-at-Large
Ann Riley, Member-at-Large
Murlean Hall, Past Chair

Individuals with Developmental Disabilities Representation

Cherie Clark	Disability Consultant	Bertram	07/01/93 - 06/30/96
Linda Desrosiers	State Consultant Deaf/Blind Education Services	Council Bluffs	07/01/93 - 06/30/96
David Greimann	Disability Consultant	Ankeny	07/01/93 - 06/30/96
Murlean Hall	Civil Rights Specialist Civil Rights Commission	Des Moines	07/01/94 - 06/30/97
Lori Peterson		New London	07/01/93 - 06/30/96
Keith Ruff	Assistant Coordinator Independent Living Center	Iowa City	07/01/92 - 06/30/95
Rick Samson	Student at Des Moines Area Community College	Des Moines	07/01/92 - 06/30/95
Vacant			

Parent/Guardian Representation

Pamela Parker	Community Services Coordinator Cross Roads of Iowa Area Agency on Aging	Des Moines	07/01/92 - 06/30/95
Carole Sage	Social Worker Iowa Department of Human Services	Charles City	07/01/92 - 06/30/95
Raymond Steffy	Suggestion Coordinator Eaton Corporation	Clarion	07/01/92 - 06/30/95
Al Takemoto	Engineering Consultant Army Management Engineering College	Bettendorf	07/01/93 - 06/30/96
Ramona TePaske	Recreation Therapist Harmony House	Waterloo	03/29/94 - 06/30/95

Principal State Agencies Required by The Act Representation

Marge Knudsen	Administrator Vocational Rehabilitation	Ankeny	07/01/94 - 06/30/97
Steven Maurer	Consultant Iowa Department of Education	West Des Moines	07/01/94 - 06/30/97
Harold Templeman	Acting Administrator Division of Mental Health/Developmental Disabilities	West Des Moines	07/01/94 - 06/30/97
Mary Ann Young	Department of Elder Affairs	Des Moines	07/01/94 - 06/30/97
Al Healy, M.D.	Director University Affiliated Program	Iowa City	07/01/92 - 06/30/95
Merv Roth	Director Iowa Protection and Advocacy Services	Des Moines	07/01/92 - 06/30/95
Linda Haley	Career Development Specialist Western Iowa Technical Community College	Sioux City	07/01/93 - 06/30/96

Local Agency Representation

Barbara Holthe	Loess Hills Area Education Agency	Logan	03/31/94 - 06/30/95
Vacant	Iowa Association of Counties		

Private Non-Profit Group Representation

Frances Brunkan	Parent Representative Alliance for the Mentally Ill	Dyersville	07/01/93 - 06/30/96
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Nongovernmental Agency Representation

Ann Riley	Executive Director Handicare, Inc.	Coralville	07/01/93 - 06/30/96
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Additional Area of Expertise Representation

Roger Chapman	Program Manager Department of Public Health	Des Moines	07/01/93 - 06/30/96
John TenPas	Department of Human Rights Commission on Persons with Disabilities	Des Moines	07/01/94 - 06/30/97

Designated State Agency

The designated state agency for the Iowa DD Council, originally designated in 1982, continues to be the Department of Human Services. The role of the designated state agency is to provide support services, fiscal receipt, account and disbursement of funds, record keeping, non-federal share of the match and assistance in securing assurances from the state. The Director of the Department of Human Services is:

Charles M. Palmer
Iowa Department of Human Services
Hoover State Office Building - 5th Floor
Des Moines, IA 50319
515/281-5452

ASSURANCES AND FISCAL INFORMATION

- A. Use of Funds. Under this plan funds will be used to make a significant contribution toward enhancing the independence, productivity, and integration and inclusion into the community of individuals with developmental disabilities in the various political subdivisions of Iowa. Some of these funds will be available to non-state government public or private entities. Federal funds used under this plan will supplement and not supplant non-federal funds, and will augment rather than duplicate or replace services available to individuals with developmental disabilities and their families who are eligible for federal assistance under other State programs. At least 65% of Iowa's allotment will be expended in the federal priority areas of system coordination and community education, community living, or employment, or on an optional state priority. The remainder of Iowa's allotment will be used for other activities relating to systemic change, capacity building, and advocacy as described under the Developmental Disabilities and Bill of Rights Act, and for planning, coordination, administration and implementation of priority area activities to implement the responsibilities of the Council. Not more than 25% of Iowa's federal funds will be allocated to the Iowa Department of Human Services, the Designated State Agency.
- B. State Financial Participation. The State of Iowa will provide reasonable state financial participation. In recent years, an annual contribution in excess of \$20,000 in indirect support and an annual cash appropriation of approximately \$35,000 have been furnished by the Department of Human Services. No significant changes are anticipated.
- C. Conflict of Interest. The Iowa Governor's Planning Council for Developmental Disabilities conflict of interest policy, adopted August 5, 1993, is designed to provide reasonable assurances that no member realizes or creates the appearance of realizing financial gain of any character, nature or amount from Council actions.
- D. Urban and Rural Poverty Areas. Special financial and technical assistance will be given to organizations that provide services, supports, and other assistance to individuals with developmental disabilities who live in areas designated as urban or rural poverty areas.
- E. Program Standards. Programs, projects and activities assisted under the plan, and the buildings in which such programs, projects and activities are operated, meet standards prescribed by the Secretary of Health and Human Services in regulation and all applicable federal and state accessibility standards.
- F. Individualized Services: Human Rights. Any direct services provided to individuals with developmental disabilities and funded under this plan will be provided in an individualized manner, consistent with unique strengths, resources, priorities, concerns, abilities and capabilities of an individual. The human rights of those individuals will be protected according to the requirements of the Developmental Disabilities Assistance and Bill of Rights Act.
- G. Minority Participation. Participation in programs funded under this plan will be geographically representative of Iowa, and will reflect the diversity of Iowa with respect to race and ethnicity. All public notices will be published in a state-wide newspaper, soliciting proposals from throughout the state. Cultural diversity has

been emphasized for all projects in the application package selection criteria and in the final contract.

- H. Intermediate Care Facility for the Mentally Retarded (ICF/MR) Survey Reports. The State of Iowa will provide the Council with a copy of each annual survey report and plan of corrections for cited deficiencies prepared pursuant to section 1902(a)(31) of the Social Security Act with respect to any ICF/MR not less than 30 days after the completion of each such report or plan.
- I. Volunteers. Maximum utilization of all available community resources including volunteers serving under the Domestic Volunteer Service Act of 1973 and other appropriate voluntary organizations will be provided for, except that such volunteer services will supplement, and will not be in lieu of, services of paid employees.
- J. Employee Protections. Fair and equitable arrangements will be provided to protect the interests of employees affected by actions under the plan to provide community living activities, including arrangements designed to preserve employee rights and benefits and to provide training and retraining of such employees where necessary and arrangements under which maximum efforts will be made to guarantee the employment of such employees.
- K. Noninterference. The designated state agency, or other office of the state, will not interfere with the Council's systemic change, capacity building and advocacy activities, budget, personnel, State plan development, or plan implementation.

PROJECTED FFY 95 FUNDING

	Federal Dollars	State Dollars	Contractor Match
Priority Areas:			
1. Employment	\$ 50,000		\$ 16,666
2. System Coordination & Community Education	\$ 475,000		\$ 158,333
Other:			
1. Planning and Administration	\$ 150,000	\$ 35,000	
2. Indirect Admin. Support		\$ 20,000	
TOTALS:	<u>\$ 675,000</u>	<u>\$ 55,000</u>	<u>\$ 174,999</u>

APPENDIX

To complete the Council's review and analysis of federal and state programs to analyze the state context, information on the following program areas was collected and reviewed.

PROGRAM AREA	IOWA STATE AGENCY CONTACTED
Education	Dept. of Education, Bureau of Special Education
Job Training	Dept. of Economic Development
Vocational Rehabilitation	Dept. of Education, Division of Vocational Rehabilitation
Public Assistance	Dept. of Human Services, Economic Assistance
Medical Assistance	Dept. of Human Services, Bureau of Medical Services
Social Services	Dept. of Human Services, Deputy Director of Service
Child Welfare	Dept. of Human Services, Division of Adult, Children and Family Services
Child Mental Health	Dept. of Human Services, Division of Mental Health, Mental Retardation, and Developmental Disabilities
Maternal & Child Health and Children with Special Health Care Needs	Dept. of Public Health and Child Health Specialty Clinics, University of Iowa
Aging	Dept. of Elder Affairs
Housing	Dept. of Human Services, Division of Mental Health and Developmental Disabilities - Housing Specialist
Technology	University of Iowa - Iowa Program for Assistive Technology
Transportation	Dept. of Transportation

In addition to contacts with the above agencies, the following state plans and reports were reviewed as part of the comprehensive review and analysis of services and supports:

- Interim State Plan for the State Vocational Rehabilitation Services Program and the State Plan Supplement for the State Supported Employment Services Program (Effective Date October 1, 1993)
- Iowa's State Management Plan for the Section 16 and 18 FTA (Federal Transit Act) Programs (July 1, 1993)
- State Plan Under Part B of the Individuals with Disabilities Education Act (FY 1993-95)
- Iowa Maternal and Child Health Services State Plan - Maternal and Child Health Services & Services to Children with Special Health Care Needs (October, 1993 to September, 1994)
- New Horizons - Emerging Trends for State Government (March 1994)
- Blue Print for Organizational Change - State of Iowa Executive Branch (December 1992)
- Iowa Comprehensive State Plan for Mental Health, Mental Retardation, and Developmental Disabilities (State Fiscal Year 1993 Update)
- Iowa IV-B Child Welfare Plan (July 1, 1993 to June 30, 1994)
- Preliminary Report of the Child Welfare Task Force (December 22, 1992)
- Mental Illness, Mental Retardation, Developmental Disabilities, and Brain Injury Service Delivery System Restructuring Task Force - Final Report (January 1994)
- Opportunity Knocks (Iowa DD Council's 1990 Report)
- Iowa - Data Tables Required Under Section 618, Individuals with Disabilities Education Act, Part III, IDEA, Part IV, Chapter 1, ECIA (07-01-92 to 06-30-93)

- Iowa - Data Tables Required Under Section 618, Individuals with Disabilities Education Act, Part III, IDEA, Part IV, Chapter 1, ECIA (07-01-91 to 06-30-92)
- Iowa - Individuals with Disabilities Education Act, Part B, Count of Children Served, (December 1, 1993)
- Iowa - Individuals with Disabilities Education Act, Part B, Count of Children Served, (December 1, 1992)
- Iowa - Chapter 1, State Operated or Supported Education Programs for Individuals with Disabilities, Count of Children Served (December 1, 1993)
- Iowa - Chapter 1, State Operated or Supported Education Programs for Individuals with Disabilities, Count of Children Served (December 1, 1992)

Following are some highlights and trends.

Title XIX - Medicaid

State Medicaid costs have apparently stabilized. Breaking from past history, Iowa has witnessed a "surplus" in the state budget for Medicaid (Title XIX). There are several hypotheses for this change including more accurate budgeting and cost saving due to implementing a managed health care approach.

Iowa has made changes to its child welfare services to add group care, treatment foster care, family preservation, and family-centered services under the Title XIX EPSDT (Early and Periodic Screening, Diagnosis, and Treatment) authority. Called the Medicaid Children's Services Initiative, this change is part of a strategy to shift spending from foster group care and to increase (through Title XIX -EPSDT) funding for in-home, preventive services. The DD Council had input in this initiative but is still concerned about where children with disabilities and their families will benefit from these child welfare services. Though not expressly prohibited from benefiting from these services, these services have been based on the prevention and treatment of child neglect and abuse rather than providing the family supports necessary to meet the extraordinary needs of a child with disabilities.

Due to 1994 State legislation, the Department of Human Services will, at least initially, be implementing a managed mental health care system for delivering Title XIX mental health services. Non-Title XIX funded mental health services (such as services funded by county governments) are also being looked at for the "managed" approach. The managed approach was advocated for as a way to control and decrease mental health care costs. It is also thought by some that the managed approach will promote competition and more cost effective community services. Iowa has contracted with one agency to manage the entire state for Title XIX mental health service.

Social Services

Iowa has relied primarily on county (property tax) and federal (Social Service Block Grant) funding for services for adults with disabilities. The majority of these funds are going for such services as sheltered workshop, work activity centers, and residential care facilities. However, there has been modest movement toward supported employment and supported living services.

Regarding the state's contribution for services, 1994 state legislation begins to set the stage for an increase in the state's share of these costs. Also, 1994 state legislation directs the counties and others to examine using a "managed" approach to providing services to people with disabilities, such as being implemented in Iowa for mental health services under the Medicaid program. It is unknown what the effects and

outcomes will be for people with disabilities and their families using a managed approach.

Transportation

Iowans with disabilities continue to identify their need for better transportation. In metropolitan areas, this need often relates to a shortage of convenient, accessible bus or public transportation. In rural areas, public transportation is very scarce or nonexistent.

The Iowa Department of Transportation (DOT) is the state agency charged with the responsibility for transportation planning, including administering the Elderly and Handicapped Grant Program. Authorized under Section 16 of the Federal Transit Act, this grant program is intended to assist private nonprofit transportation services meeting the special needs of persons who are elderly or have disabilities. Previously, staff from the DOT have stated that, in general, they have not heard directly from the people with disabilities about their transportation needs. The DD Council completed a study to examine the transportation needs of Iowans with developmental disabilities and to develop applicable recommendations. Based on this study, the Council funded a project to increase the effective planning for the transportation needs of people with disabilities. Currently the DD Council is funding four mini-grants to assist regional transportation planning with the participation of people with disabilities and others.

Education

In addition to the (Iowa) State Plan Under Part B of the Individuals with Disabilities Education Act (IDEA), the data tables and related reports, prepared by the Iowa Department of Education under section 618 IDEA, were reviewed. Though advancements have been made, it is not uncommon for children with disabilities to receive public education in segregated classrooms and many do not attend their neighborhood schools (the schools they would attend if they did not have disabilities).

The Iowa Department of Education, Bureau of Special Education is in the process of revising its administrative rules for educational services for children with disabilities. The proposed rules endorse regular class inclusion and the proposed policy direction is consistent with the Individuals with Disabilities Education Act. However, when the rules were published for public comment, concerns were expressed by parents and advocates that the proposed rules would eliminate maximum class size and procedurally would delay parents' access to due process in the event of a dispute. The Department is currently reviewing the public comment.

Vocational Rehabilitation

The Rehabilitation Act Amendments of 1993 had a significant effect on Iowa. In the past, the federal funds available for independent living centers have gone to the Iowa Department for the Blind. Because state agencies are no longer eligible for these funds, these federal funds are now going to four private, cross-disability independent living centers in the state. These centers serve only about one-fourth of the State's 99 counties.

The Iowa Division of Vocational Rehabilitation also has a new director, Marge Knudsen. Ms. Knudsen, who also serves on the DD Council, has expressed her support for centers for independent living, fully implementing the spirit of the Rehabilitation Act Amendments, and the employment of people with disabilities, including people with more involved disabilities.

Technology

Iowa is among the recipients of a development grant authorized under the Technology-Related Assistance for Individuals with Disabilities Act. This grant is administered by Iowa's University Affiliated Program and is known as the Iowa Program for Assisted Technology (IPAT). IPAT provides training and information and referral information on equipment, manufacturers, vendors, sources of funding for assistive technology and referral to free legal advocacy services on issues relating to assistive technology.

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