

LOOKING TOWARD THE FUTURE



THE MINNESOTA GOVERNOR'S COUNCIL ON DEVELOPMENTAL DISABILITIES

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SECTION ONE: DEFINING WHAT IS IMPORTANT FOR THE FUTURE – to state clearly, to all concerned, what the Governor’s Council on Developmental Disabilities (GCDD) thinks is important and how we want the future to look. Together, we can make a world that welcomes, respects, and supports all people with developmental disabilities as citizens, neighbors, and friends. This Statement of Intent outlines our view of where we are going. PAGE 3

SECTION TWO: REVIEWING THE YEAR – to report on what the GCDD achieved in the year October 1, 2000 to September 30, 2001. Over the year, the GCDD invested \$1.2 million to increase the independence, productivity, self determination, integration and inclusion of people with developmental disabilities and their families. PAGE 7

SECTION THREE: CELEBRATING PROGRESS – In October 2001, the GCDD celebrated its 30th anniversary. Its work has led to changes in state and federal laws and policies; the development of new approaches; and the empowerment of thousands of people with developmental disabilities, their families and friends in Minnesota and around the world. PAGE 19

WHERE ARE WE GOING

In 1970, the United States Congress established and began to fund state councils on developmental disabilities. Today, the purpose of state councils is

- to engage in advocacy, capacity building, and systemic change activities that will
- contribute to a coordinated, consumer and family centered, comprehensive system of community services, individualized supports and other forms of assistance that
- enable individuals with developmental disabilities to exercise self determination, be independent, be productive, and be integrated and included in all facets of community life.

Consistent with that purpose, our mission is:

- to provide information, education, and training that will
- build knowledge, develop skills, and change attitudes that will lead to
- increased independence, productivity, self determination, integration and inclusion (IPSII) for people with developmental disabilities and their families.

In January 2002, the GCDD consolidated its position on a range of social issues. These positions outline the direction the GCDD wants us all to take in the future.

Underlying these positions is a fundamental shift in the way we think about people with developmental disabilities and their futures. In the past, we have been preoccupied with services and programs that would allow people with developmental disabilities to have decent lives. Over the years, we refined our ideas about the purpose of those services and programs. But fundamentally, a lot of time and energy was devoted to changing services so they would assist consumers to lead better lives.

Over time, however, our perspective has changed. We have come to see people with developmental disabilities as people who act on the world, who are in the world with everyone else. We look for ways to increase their power (and that of their families and friends) to shape the world they live in. We look for ways to ensure that people with disabilities stay in the world, among us. We struggle to make sure that all citizens have equal access to places and services. We work to make sure that people with developmental disabilities can dream about and actually experience the same kind of life as other members of the community.

POSITION STATEMENTS

Taken together, these statements describe key features of the way we want the world to be over the next ten years:

The Rights of Citizenship People with developmental disabilities are citizens with the same rights to life, liberty, the pursuit of happiness and equal treatment under the law as other citizens. These rights should be protected in legislation. The Americans with Disabilities Act should be enforced to protect the rights of individuals with developmental disabilities.

The Power of Choice and Self Determination People with developmental disabilities have a right to decide how they live and have maximum control over their own lives. People have a right to decide how they live, where they go to school, where they work, what they do in their spare time, and who their friends will be. They have a right to make choices based on good information about their personal goals in life.

Contribution and Community People with developmental disabilities should get the support they need to be a real part of the community and participate with people who do not have disabilities. We must develop the capacity of neighborhoods and communities to include people with disabilities. People with disabilities can contribute to community life and the creation of a sense of community. People with developmental disabilities should be supported, assisted and educated to become active members on community boards and committees.

An Accessible World As much as possible, the services that people need and the places where services are provided should be designed so everybody can use them.

The Power of Communication and Technology All people with disabilities, right from birth, are entitled to opportunities to communicate in the most effective manner. Other people should pay attention to what they have to say, however they say it. People with developmental disabilities should have the chance to use assistive technology that can help them be more independent and have more control over their lives, in all aspects of their lives.

Freedom from Harm People have the right to live free from abuse, neglect, injuries and preventable death.

Family Support The family is the best source of support for a person with developmental disabilities. Families should have control of resources so they have as much choice as possible over the supports and services they receive. Family support services should be flexible and individualized so that children with disabilities, and their parents and siblings get the support they need; build on the family's network of supportive neighbors, extended families, friends, and community networks; affirm and strengthen families' cultural, racial and linguistic identities; and strengthen their ability to function in a multi-cultural society.

POSITION STATEMENTS

Home and Housing People with developmental disabilities have the right to freely choose where and with whom they live. All people should have the opportunity to live in homes in their local communities, including owning a home of their own.

Education All students with developmental disabilities should get all the support they need for self-determination, participation, and choice. This includes a free and appropriate public education in classes with their peers without disabilities, early intervention services, extended school year programs, and a smooth transition to employment and/or advanced educational and training opportunities.

Employment Employers should directly hire people with developmental disabilities in a wide variety of jobs that match their skills and abilities. People with developmental disabilities should be supported to work competitively in an inclusive workplace and have careers – the opportunity to be promoted, greater choice about what they want to do, receive better pay, take on more responsibilities and different kinds of work, and have better working conditions. They should have the option to control and direct the funding and resources allocated on their behalf for employment, and fully participate in all state and federal job programs.

Services That Make Sense Service coordination should respect the right of each person to make choices based on good information, assuring that plans are person centered and that each person receives high quality services. Funding for supports and services must follow the person rather than be tied to a facility or location.

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Every year the GCDD prepares an annual report for the Administration on Developmental Disabilities (ADD). The annual report describes what the GCDD did with the federal funding and what was achieved.

STRATEGIC DIRECTION STATEMENT

In its Three Year Plan for October 2000 to September 30, 2003, the GCDD described the following strategic direction:¹

By 2003, the GCDD will be recognized as a national leader in advancing the independence, productivity, integration and inclusion (IPII) of people with developmental disabilities and families through the primary products of -

- **Partners in Policymaking®**
- **Communications and Training**
- **Quality Improvement.**

The strategies within these three areas are as follows:

Partners in Policymaking

- Partners in Policymaking, a leadership training program designed for adults with disabilities and parents of young children with developmental disabilities, will be held annually.

¹ In November 2000, the DD Act was amended and state developmental disabilities councils moved to a five-year planning cycle. The current Five-Year Plan covers October 1, 2001 to September 30, 2006. The components of the plan are essentially the same as the original Three Year Plan, with the addition of a goal to support and strengthen self advocacy.

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- Workshops for Partners graduates will be offered quarterly to strengthen personal leadership skills.
- Longitudinal studies of Partners graduates will be conducted annually.
- Cultural outreach programs will be conducted annually in the African American, American Indian, and Hispanic communities for parents of children with developmental disabilities.
- A pilot program, Partners in Policymaking for Employers, will be tested with Minnesota businesses aligned with the Baldrige framework. This framework promotes the best of business standards to improve performance, achieve strategic goals, and increase business results within a customer driven environment.

Communications and Training

- Publications and resource materials will be available free of charge in accessible formats.
- All products and services will be converted to web accessible formats in accordance with Electronic Government Services objectives.
- Training conferences will be cosponsored annually.

"I speak up and I have become more independent."

Partners graduate

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Customer Focus and Quality Improvement

- Research will be conducted on customer needs, requirements, and expectations. Customer satisfaction data will be collected systematically.
- The GCDD and suppliers will increase their knowledge, understanding, and application of the Baldrige framework.

WHAT WE DID, WITH WHOM, WITH WHAT RESULTS

PARTNERS IN POLICYMAKING

As a result of the Partners in Policymaking program:

- 33** individuals graduated from the Partners program bringing the five-year total (1997-2002) to 146 graduates. The Partners curriculum covers 11 topics in eight weekend sessions. Participants are involved in a minimum of 128 hours of competency based instruction. They learn about best practices in education, technology, housing, and employment; and gain knowledge and experience in working with elected officials for systems change.

“Partners is the best thing I have ever done.”

Partners graduate

At the end of the program, participants were asked to rank their independence, productivity, integration and inclusion (IPII) on a five point scale, where 5 is the highest. Their average scores were:

Independence: 4.2

Productivity: 4.1

Integration/Inclusion: 4.2

In each case, this was an increase over their rankings at the beginning of the class.

In years past, Partners graduates were asked if their IPII levels had increased because of the Partners program. In the four classes between 1997 and 1999, graduates most often reported an increase in their independence (from 83% to 100%). Slightly fewer reported an increase in integration and inclusion (from 78% to 85%). Not surprisingly, because of the nature of the Partners curriculum, graduates are less likely to report increases in productivity levels (from 56% to 78%).

"I got an apartment by myself. I started the job of my dreams."

Partners graduate

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Workshops for Partners Graduates

Four workshops were held for 46 graduates from previous Partners classes. The workshops focused on facilitation and negotiation skills.

At the end of the workshops, participants ranked their IPII levels as follows:

Independence: 4.6

Productivity: 4.7

Integration/Inclusion: 4.9

Partners graduates certainly appear to see themselves as increasing their IPII, both as a result of follow up workshops and also because they continue to use their skills over time.

Longitudinal Study of Partners Graduates

During the year, a total of 530 Minnesota Partners educated elected officials at county, state and federal levels, and distributed information on current issues. They actively participated in forums and meetings about services and supports that work, gaps in services, and ways to improve the system and remove barriers so that service delivery systems are more responsive to individual and family needs.

Cultural Outreach

In 2000, thirty African American parents of children with developmental disabilities participated in a training program that provided personal support and

“I learned about rights and responsibilities.”

Cultural Outreach graduate

introduced the concepts of the Partners program. As a result of the training, participants reported significant increases in their IPII:

Independence: 94%

Productivity: 95%

Integration/Inclusion: 95%

Similar outreach and training programs have been held in the American Indian and Hispanic communities. As a result of these efforts, at least 17 participants have gone on to become Partners graduates.

In 2000, eight American Indian parents and 12 Hispanic parents of children with developmental disabilities participated in focus groups conducted around family support needs, requirements, and expectations. The focus groups documented and clarified service gaps in the minority communities, and prompted an interest among the parents in forming a Family Support Council.

Partners for Employers

An e-learning prototype was developed for Partners for Employers. The complete on-line course will include home pages for employers, family members, persons with developmental disabilities, and professionals/service providers. The prototype included resources, best practices, interactive exercises, tips and tools, and facts and questions.

"All voters should have a copy of Making Your Case."

Customer comment

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Thirty-two hours of training on quality principles, based on the Baldrige Criteria were provided at Rochester Community and Technical College.

In addition, 16 people with developmental disabilities were supported as employees to prepare resource packets for the Parents in Policymaking weekend sessions.

COMMUNICATIONS AND TRAINING

Publications and Resource Materials.

The GCDD is known and respected worldwide for its publications and resource materials.

In this one year, 2,069 orders were received, resulting in the distribution of 30,103 publications and 5,599 CD-ROMs. Publications and resources on person centered planning are in particularly high demand. *Making Your Case*, a booklet that offers techniques and insights for effective communication skills in the legislative process and how to positively influence public policy at all levels of government, was updated. More than 3,000 copies of the updated edition were distributed during the past year.

For three years, our customers have said our publications are useful and helpful between 97% and 99% of the time. When asked to rate our publications on a scale of 1-10 (with 10 as highest), the average score this year was 9.2

The GCDD responds to technical assistance requests on a daily basis. During the year, a total of 1,209 technical assistance requests were handled.

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“The CR ROM is an incredibly detailed and accurate history.”

Customer comment

Web-Accessible Products.

The Learning Center and *Parallels in Time* are both available online (<http://www.mnddc.org> OR <http://www.mncdd.org>) and on CD-ROM. *Parallels in Time* traces the treatment, perceptions, and types of services available to people with disabilities from B.C. to the present. *The Learning Center* contains over 10,000 pages of GCDD documents. New publications and resources are also posted on and available through the web site.

The GCDD’s web site is the largest on the State of Minnesota server.

Training Conferences

The GCDD cosponsored ten training events/conferences with local and state disability organizations – ACT, Inc.; Arc Central MN; Arc Hennepin-Carver, Arc MN, Arc Southwest MN, Brain Injury Association of MN, Metro Self Advocacy Council Consortium, MnDACA, MN SILS, Twin Cities Autism Society.

The conferences promote leadership development among people with developmental disabilities and their families. During the past year, 2,268 people attended.

“I have applied Baldrige to my family, my school, and my job. It works!”

Council member

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As a result of these training conferences, participants reported the following increases in their levels of IPIL:

Independence: 77%

Productivity: 79%

Integration/Inclusion: 79%

Customer Focus and Quality Improvement

The GCDD is committed to listening to its customers. To act on this commitment, it has adopted the Baldrige Framework – a continuous improvement framework that is focused on the customer, based on facts, and directed toward results.

The Framework has guided the GCDD’s efforts to design a systematic process of surveying customers and gathering satisfaction/dissatisfaction data to ensure that GCDD members, staff, and suppliers are focused on quality performance and improving business results.

Customer Research

A statewide customer satisfaction survey was conducted this past year. The purpose of the survey was to determine how people with developmental disabilities evaluate the quality of products and services they receive from government agencies and suppliers; determine current levels of satisfaction with IPIL; and identify the obstacles they face in day-to-day living.

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One thousand questionnaires were sent out and 300 were returned. Highlights of the survey are as follows.

- In the business world, the standard is 80% satisfaction – anything less is a signal that your business is in crisis. None of the satisfaction data from the survey was above 80%.
- 60% of respondents were satisfied with their level of independence.
- 62% of respondents were satisfied with their level of productivity.
- 64% of respondents were satisfied with their level of integration.
- 55% of respondents were satisfied with their level of inclusion.
- 25% of respondents were dissatisfied with the education/special education services they were receiving. Almost one third of the respondents believed their concerns were not addressed promptly or professionally.
- All levels of government received low satisfaction ratings. County and state government each received a rating of 5.5 (scale of 1 to 10 where 10 is the highest). The federal government received a rating of 4.9.

“The GCDD has embraced the Baldrige Criteria to improve every facet of what it does and how it operates to improve business results.”

Minnesota Council for Quality

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Quality Improvement

In 1999, the GCDD received the Achievement (Gold) Award from the Minnesota Council for Quality, the highest award received by a government entity. This award level demonstrates sound and effective business approaches and practices that are responsive to the overall requirements of the Baldrige Criteria.

GCDD members and staff completed a total of 440.5 hours of training on the Baldrige Framework and quality principles to improve performance, align all activities with IPII results, and focus service design/delivery around customer needs, requirements, and expectations. Suppliers completed 70 hours of quality improvement training.

The GCDD is generally recognized as having made a difference during the past three decades. New ways of thinking about the world and life experiences of people with developmental disabilities have been identified and made accessible to citizens across the country. New ways of thinking result in new demands on the system.

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The Emergence of the Developmental Disabilities Act.

In 1962, President John F. Kennedy's Panel on Mental Retardation firmly put issues facing people with developmental disabilities on the public policy agenda. In 1963, federal legislation created a construction program to:

- Build research centers.
- Construct public and nonprofit clinical facilities (University Affiliated Facilities or UAFs) for inpatient and outpatient services, and the training of physicians.
- Build community facilities.

In July 1964, federal planning funds were awarded to Minnesota under P.L. 88-156, beginning a process that would last three and one half years. Governor Karl Rolvaag appointed the 25 member Minnesota Mental Retardation Planning Council to investigate, deliberate, recommend, and implement action "to remedy the effects of many long years of neglect."

MAKING A DIFFERENCE

In 1966, a two volume comprehensive plan contained hundreds of recommendations for needed improvements in services, the regional deployment of services, and facilities. This statewide construction plan would qualify Minnesota for federal matching funds.

The language of the recommendations is repeated in much of what is now being written, though with quite different meaning. Recommendations contained phrases that resonate today: earning to live; the dignity of work; a house must be a home. At that time, the terms referred to smaller, though still segregated programs. The emphasis was on reforming institutional services rather than eliminating them. There were also calls for employing people with developmental disabilities in government departments and recognizing the fact that “all other avenues for maintenance in the community” should be pursued before deciding on residential placement.

The Developmental Disabilities Services and Facilities Construction Act was passed in 1970. Each state was required to establish a state council on developmental disabilities. The council would be responsible for setting the direction and submitting a state plan. A designated state agency would be responsible for administering and supervising administration of the state plan.

The DD Act ensured that services would include people with conditions in addition to mental retardation – cerebral palsy, epilepsy or neurological conditions that originate before the age of 18 and are expected to continue for a long time and result in substantial limitations.

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“Even decades later, the council has far exceeded my expectations.”

Governor Wendall Anderson

State councils were expected to fill service gaps in 16 areas: diagnosis, treatment, day care, training, education, recreation, follow-along, transportation, evaluation, personal care, domiciliary care, special living arrangements, sheltered employment, counseling, protective legal services, and information and referral.

THE FIRST DECADE IN MINNESOTA

On October 28, 1971, Governor Wendell Anderson announced the appointment of a 20-member Developmental Disabilities State Planning and Advisory Council.¹ During the 1970s, the Council was involved with activities that had, or were intended to have, an impact on changing the system – service grants, regional planning and development, and planning efforts to develop a comprehensive system and bolster community alternatives.

Service Grants

In these early days of community service development, the GCDD funded a number of alternatives to institutional care. Some of these efforts were the precursors of much more developed family support services and Medicaid waived services in the 1980s.

¹ In 1976, the name changed to the Minnesota Governor’s Planning Council on Developmental Disabilities. In 1995, the Council became the Minnesota Governor’s Council on Developmental Disabilities.

MAKING A DIFFERENCE

In the 1970s, the GCDD began funding a number of innovative projects:

- 1972** Early intervention home teaching model
- 1973** Training for University of Minnesota personnel who provide services to those with profound disabilities
- 1973** Access to post secondary education
- 1973** Law school curriculum related to developmental disabilities
- 1974** Training for homemaker services to support parents with developmental disabilities
- 1974** Public information campaign, "Project People"
- 1974** Household survey to determine prevalence of disabilities
- 1974** Advocacy and transition planning for adolescents
- 1975** Integrated leisure activities and citizen advocacy
- 1976** Self controlled residential settings and sheltered employment placements in local businesses
- 1977** New case management approaches
- 1979** Statewide case management training

The GCDD also funded legal advocacy through the Legal Aid Society. This predated the inclusion of Protection and Advocacy in the mandate of the DD Act.

In the mid to late 1970s, several changes in Minnesota helped to focus efforts that had been supported earlier by demonstration grants. In 1975, zoning for group homes was established in state statute. In 1976, the Family Subsidy Program was created to support children with developmental disabilities

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“The CAIR project was the first and most comprehensive study of deinstitutionalization.”

Miriam Karlins

to live with their families. In 1979, the Minnesota Community Social Services Act mandated county authority over the funding, planning and administration of community social services, including ensuring the means of facilitating access to appropriate services for people with disabilities.

The usefulness and impact of service grants grew in the middle of the decade when they were tied to the rapidly expanding demands for a comprehensive system and the development of community alternatives. Momentum was developing for a much more focused effort on deinstitutionalization and the development of community alternatives. The grant resources were dedicated to developing a statewide systems plan, advocacy and case management.

A New Direction for Planning

In 1974, the GCDD received funds under P.L. 91-517 to create a process for establishing community alternatives for individuals with developmental disabilities. These funds were used to support the Community Alternatives and Institutional Reform (CAIR) Project and led to the development of the 1976 GCDD goals related to Community Alternatives and Institutional Reform:

- To develop strategies and guidelines for implementing a statewide continuum of community-based residential and supportive services based on the CAIR Report.

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- To encourage legislation and agency planning which will improve the quality, extent and scope of services provided in state and private residential facilities.
- To improve statewide programs by funding development of model programs in areas where deficiencies have been identified.

Regional Planning

Throughout the 1970s and until 1986, the GCDD, as part of the State Planning Agency, funded projects with a regional focus. Regional Development Commissions were established by state law to facilitate intergovernmental cooperation and ensure coordination of federal, state and local comprehensive planning programs. Regional Development Commissions were funded by the GCDD to carry out regional planning for persons with development disabilities and support regional Developmental Disabilities Committees.

These planning grants brought people together to discuss issues and develop community development strategies on a regional level. Information flowed freely between the GCDD and the community. A number of studies and projects were initiated in areas that preceded state attention such as respite care, minority involvement, financial disincentives, and employment programs.

Further Changes in the DD Act

The DD Act was amended in 1975 and 1978. These changes captured many of the directions Minnesotans were promoting.

The 1975 Act added a bill of rights and mandated the establishment of a Protection and Advocacy System in every state. State plans had to address and support efforts designed to eliminate inappropriate institutional placements and improve the quality of institutional care. Autism and dyslexia were added to the list of conditions defined as developmental disabilities. Funding levels were increased for both state developmental disabilities councils and UAPs, and funds were also appropriated for “Special Projects” with a national scope (now called Projects of National Significance).

The 1978 amendments eliminated references to disabling conditions and added functional definitions.² The age of onset also changed from 18 to 22 years.

Four federal priorities replaced the 16 basic services and included case management, child development, alternative community living arrangements, and nonvocational social development services.

² Developmental disability is defined as a severe, chronic disability of a person attributable to a mental or physical impairment, is manifested before age 22, is likely to continue, results in functional limitations in three or more major life activities, and reflects the need for lifelong services.

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THE 1980s - A WHOLE NEW BALL GAME

Strategies Guided by Clear Vision

By the beginning of the 1980s, it was increasingly clear that the DD Act was not going to be a major source of funding for direct services. Systemic change would require carefully thought out strategies that would:

- Bring new ideas to people and get them talking.
- Be clear about the vision for the future so that actions have a future oriented context.
- Engage in critical policy analysis and educate policymakers about appropriate courses of action.

In the early 1980s a number of key developments set the stage for dramatic possibilities if they could be harnessed and used intentionally to achieve a new vision.

- The *Welsch* Consent Decree required the State of Minnesota to substantially reduce the number of people in regional centers by 1987; improve conditions and staff/resident ratios in the regional centers; and develop community services for people leaving the regional centers.
- In 1981, the Home and Community Based Waiver allowed states to use Medicaid funding to finance an array of community services.
- Also in 1981, Minnesota Rule 185 mandated county case management and required a needs assessment, an individual service plan, and ongoing support.

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From the early 1980s, the GCDD embarked on a series of strategies to use what leverage it had not just to make plans, but to effect systems change. The effectiveness of this strategy was recognized early on.

In 1986, GCDD was cited as one of ten exemplary human service planning agencies - in part because the GCDD demonstrated one of the distinctions between merely making plans and true strategic planning. Bill Benton³ described some of the characteristics of exemplary planning:

Plan making is the process of preparing a document.

Planning is the process of translating vision into reality.

Planning attempts to make the future different than it otherwise might be.

Plan making makes no difference at all.

The GCDD has a history of trying to make a difference, to shape the future rather than simply be shaped by it.

³ *When the Going Gets Tough: Ten exemplary human services planning efforts* – Final Report. Prepared by Urban Systems Research & Engineering Inc. for the Office of Program Development, U.S. Office of Health and Human Services. September 1985.

“The Policy Analysis Series is very impressive, possibly the most careful work now being done anywhere in this area.”

Burton Blatt

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State Plans, Policy Analysis, and Briefings

State Plans

From the beginning, state councils have been required to develop state plans. Historically, these plans have documented the status of services and state agencies; articulated the mission and mandate of the GCDD; identified priorities, goals and objectives; and reported on progress toward previous goals and objectives.

While state plans have captured information about what was going on in the State at a given period of time, and how federal funds were spent, these plans are essentially compliance documents.

The *Welsch* Consent Decree

Following the *Welsch* Consent Decree, the GCDD conducted a number of studies focused on issues surrounding the process of deinstitutionalization and the dynamics of systems change. The Policy Analysis Series presented the findings from the studies.

One commentator of the times described the role of these powerful, but modest looking documents:

... in 1981 the Council had a unique opportunity to influence the course of history for persons with developmental disabilities in Minnesota, not by funding direct service projects, but by facilitating the forward movement of deinstitutionalization, set

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“The State Hospital study could have turned into an embarrassing loser. Instead it was well researched, well documented, with sound recommendations. Success was due to solid staff work.”

Gus Donhowe

in motion by the *Welsch* Consent Decree but slowed by a thicket of competing and often contradictory statutes, rules, traditions and turf. The Council ... set about imposing order on the system by describing it in lucid prose, and making recommendations both rational and implementable for change. In the series of 22 policy analysis papers, [the Council] has tackled all the issues relating to the successful development of an array of community choices for persons with developmental disabilities and their families, including creative alternatives for persons currently giving, directing or licensing services, a most impressive body of work.

Betty Hubbard, St. Paul Arc

In 1981 and 1982, the series focused on issues specifically related to deinstitutionalization. In 1983, and continuing through 1990, the Policy Analysis Series reported on the impact of various grants and research activities supported by the GCDD. These documents would be useful at the federal level for gathering support for changes in policy and funding for family support, supported employment, the affirmative use of technology, and case management. The research ensured that the learning could be substantiated and shared with others.

In 1984, the Minnesota Legislature mandated the study of the possible economic effects from consolidation, conversion, or closure of state hospitals. The GCDD was given the responsibility for conducting the study and coordinating the plan. The Institutional Care and Economic Impact Board submitted

**“The briefing book, *Developmental Disabilities and Public Policy*,
is a superb summary of current issues.”**

Bob Gettings

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recommendations and findings to the Legislature on January 31, 1985. The report was contained in eight technical papers, a second Policy Analysis Series prepared by the GCDD and entitled *Issues Related to State Hospitals*. An abbreviated policy briefing publication, *Minnesota’s State Hospitals: Mental Retardation, Mental Illness and Chemical Dependency*, was also developed.

Policy Briefing Documents

Throughout the 1980s, the GCDD developed a series of other documents that have become renowned for their efforts to lay out, in accessible ways, an agenda for change.

Developmental Disabilities and Public Policy: A Review for Policy Makers (January 1983) was the first of a new kind of publication, providing information about persons with developmental disabilities, trends in community services, and policy issues and alternatives for the 1980s. The idea was to create an accessible, attractive booklet that delivered the ideas.

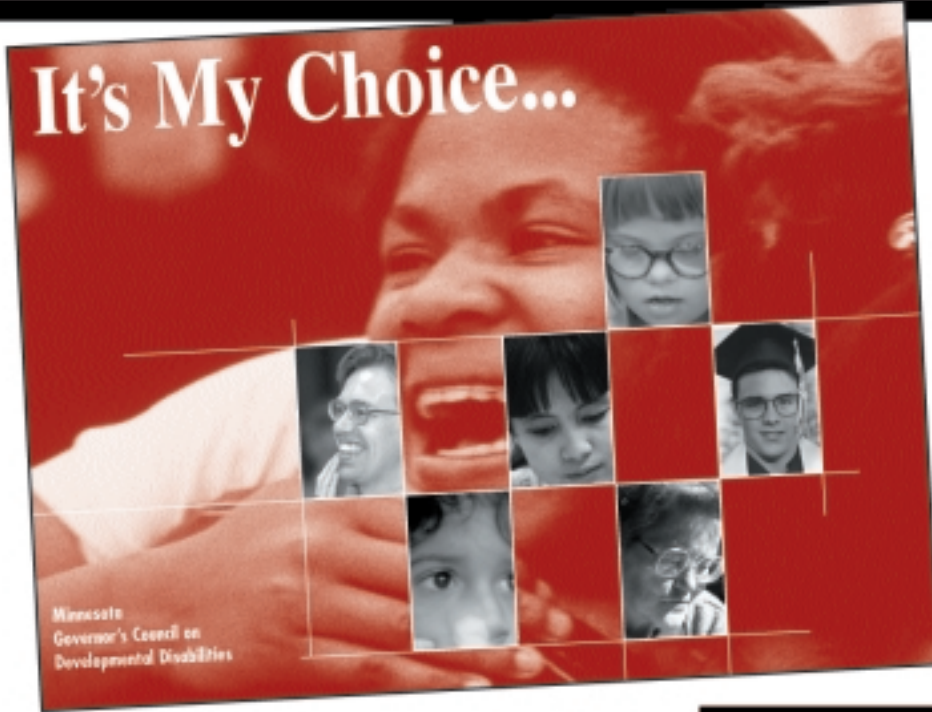
In a review of ten exemplary human service planning efforts, Urban Systems Research & Engineering, Inc. described the marketing strategy:

Like the policy papers, this document was widely disseminated, but in a particularly noteworthy manner. Instead of simply distributing the document by mail, the brochure was personally delivered to key policy makers (e.g., state legislators) by a constituent involved in the developmental disability network.

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“Like all good writing, your publications give the reader the illusion of simplicity. The writing is clear, brief, and accurate.”

Bob Perske



“We need 50 copies of *A New Way of Thinking*.

I don't need to talk. Everything is in there.”

Ian Pumpian

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Developmental Disabilities and Public Policy laid the groundwork for a concerted effort to remove the disincentives to community living and urged Medicaid reform. It described the difference between a provider driven and a consumer driven system.

Other documents followed:

- *Towards a Developmental Disabilities Policy Agenda: Assuring Futures of Quality* (1984) identified what was currently happening in the state, what we knew to be possible, and a goal for the future. It articulated a vision of the future - supporting communities to act responsibly, to be competent, to recognize and support the citizenship of Minnesotans with developmental disabilities. It articulated a description of what a community, responsive to people with disabilities, would be like.
- *A New Way of Thinking* (1987) focused on new ways of thinking (paradigm shifts) about basic issues important to the quality of our lives - a real home, a real education, real work, sustaining relationships. A companion videotape was developed. Over the next decade, 50,000 copies of *A New Way of Thinking* were distributed. It was reprinted in 1998 and 2000, and has been translated into several languages. Many saw it as a “break through” document. The videotape won awards and was aired on the local NBC affiliate.

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“The Mental Health Commission was an incredible learning experience.

Thank you for shepherding us through all the meetings.”

Norma Schleppegrell

The Mental Health System

The *Welsch* Consent Decree provided one context for the GCDD’s influence on systemic change. A second major area was the mental health system.

In 1985, advocates met with Governor Rudy Perpich’s speech writer and suggested that a blue ribbon panel was needed to look at the mental health system. The Governor’s Commission on Mental Health was announced on June 14, 1985, to look at several aspects of mental illness, and issues related to mental health services and policy. The GCDD was called upon to provide technical assistance and staff support to the Commission.

While some positive trends and exemplary services were highlighted, one sentence in the Commission’s report was widely quoted:

In other words, the “system” is, to a significant extent, divided, inconsistent, uncoordinated, undirected, unaccountable, and without a unified direction.

Recommendations were organized according to three themes: making a commitment, organizing to meet the commitment, and ensuring that the commitment was met.

The 1986 Legislature enacted a mission statement for Minnesota’s mental health system beginning: “The Commissioner of Human Services shall create and ensure a unified accountable, comprehensive system of mental health services.” In 1987, the Comprehensive Mental Health Act was passed. It

“I very much enjoyed the family support paper.

Please send another copy.”

Wolf Wolfensberger

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required all 87 counties to provide a continuum of specific services for persons with mental illness, some local and some on a regional basis.

Grants - Leverage for Change

The GCDD's ability to use grants to support new initiatives was critical in its efforts to impact systemic change. However, three year planning cycles were episodic.

FFY 1981 to 1983 - Respite

In the first three years of the 1980s, the GCDD's priority was the development of alternative community living arrangements. Grants supported respite programs as part of an overall strategy to increase the availability of responsive family support programs and funding for meaningful community living arrangements.

Over the three years, grants were awarded to 17 projects; eight projects spanned two or three years:

- Sixteen projects focused on respite.
- Direct services were provided to 1,000 people.
- A total of 2,700 people received information and referral services.
- At least nine of the projects remained in operation during the 1980s because of continuation funding from other sources.

The funded projects became the basis for a paper in the Policy Analysis Series. Other papers in the Series dealt with the lack of respite as a factor in institutional admissions, the positive impact of the state's family subsidy pro-

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“The McKnight Foundation chose the GCDD to administer the umbrella grant program because of the technical expertise of their staff.”

Carol Berde

gram, the emergence of cost effective programs supporting families, and a literature review about respite services. The results of this work came together in 1986 Congressional testimony about the Community and Family Living Amendments and the need for Medicaid reform.

The groundwork was laid for a number of system changes in caregiver support and the use of Medicaid funding.

FFYs 1982 to 1985 - The McKnight Foundation Grant

In 1982, the GCDD received a three year, \$900,000 grant from the McKnight Foundation. Projects were funded in the following areas:

- Regional problem solving – 25 projects were funded; 29 workshops were held and 976 people attended; and 1,083 people were directly served.
- Increased accessibility in Developmental Activity Centers (DACs) – 20 grants to 17 DACs benefited 158 persons with developmental disabilities.
- Projects serving specific disability groups – Five grants resulted in 21 workshops attended by 326 persons; a total of 125 persons with autism or epilepsy were served directly.
- Training to direct care staff, administrators, and managers – 63 workshops were conducted for 2,174 people on organization and management development, and 30 workshops for 1,110 people on direct care services (individual programs and behavior management).

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In addition to specific project activities, the following outcomes resulted:

- Services for children (birth to five) were coordinated.
- An information and referral directory was developed.
- Staff were recruited and trained to provide outreach services to minority children.
- A used equipment referral service was developed.
- Various employment opportunities were developed, including self employment.
- Day care providers were trained to provide services to children with disabilities.
- A manual and teaching guide for model educational programs for people with epilepsy was developed.

The long term impacts of these grants resulted in systemic change in two key areas:

- The Assistive Technology Project was the beginning of a pioneering emphasis on the creative and practical use of technology to empower people and enable them to control their lives and environments. The literature review was the basis for a 1984 issue of the Policy Analysis Series (No. 22).

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“I would like to compliment the Council on the high quality and aesthetics of the Technology report.”

Robert Bruininks

In 1985, Governor Rudy Perpich appointed a 19 member Issue Team on Technology for People with Disabilities. This led to the development of the MN Governor’s Advisory Council on Technology for People with Disabilities. Support of this state level initiative preceded the passage of the federal law in 1988, the *Technology-Related Assistance for Individuals with Disabilities Act*, which placed a major emphasis on increasing the availability of assistive technology.

- The Direct Care Training Initiative that began under the McKnight Foundation grants has, over time, resulted in a certificate program offered through the state’s community and technical colleges. In 1989, funding provided for the development of five training modules on technological adaptations, alternatives to behavior management, communication, positioning, and individual planning.

The 1991 Legislature directed the State Board of Technical Colleges, with task force assistance, to develop education and training materials for direct care providers, including families, who provide services to persons with developmental disabilities. By 1996, a total of 30 Technical Colleges offered 25 courses that were funded by the GCDD, and a library of ten value based and competency based training modules was purchased. In 1998, fifteen students completed a diploma program for direct service staff, 187 individuals completed courses via distance learning, and 593 individuals received hourly training.

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FFY 1983 - 1986 Behavior Management and Community Employment

In 1982, the GCDD held public hearings to guide its decision on a priority for the next three-year state plan. Testimony indicated that needs were great in two areas - assistance to work with people who have behavior problems, and finding employment in the community for people with developmental disabilities.

Between 1983 and 1986, grants funded 18 projects and 1,132 people were served.

The initial focus of the grants was on general improvements in day programs - staff training, interagency cooperation, direct program support to individuals, and transportation. In addition, there were more targeted efforts to assist individuals to get and keep jobs in the community.

Project outcomes included:

- Increased income for employed individuals with disabilities.
- Regular contact with people without disabilities.
- Fewer behavior management problems among people who had jobs.

The community employment grant recipients continued the projects that were funded by the grant. At least one project achieved 100% community placement. The long term impact of these efforts certainly increased because the projects remained in operation beyond the initial funding period.

“Minnesota has done an excellent job in defining the issues, identifying opportunities, and setting solid objectives in supported employment.”

Council of State Planning Agencies

The McKnight Foundation grants and the GCDD’s service grants kick started a process toward change in supported employment. In 1985, the U.S. Office of Special Education and Rehabilitative Services (OSERS) approved a five year grant that resulted in the establishment of the Minnesota Supported Employment Project (MnSEP).

Amendments to the Rehabilitation Act (P.L. 99-506) in 1986 established a federal program of state grants for supported employment for people with severe disabilities.

In 1987, the Minnesota Legislative Task Force on Supported Employment was created. In 1988, the Task Force recommended maximizing federal funds and encouraging the expansion of federal initiatives; increasing state funds to expand community/supported employment which included \$4 million in new funding; and redirecting existing school and county funds to support community/supported employment.

Throughout the 1980s, the GCDD continued to provide information related to supported employment. The Policy Analysis Series was again used to inform others about the outcomes of the grant projects, research into the effectiveness of supported employment programs, and strategies for financing supported employment with state and federal funds.

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FFY 1986 to 1989 Case Management

As early as 1977, Minnesota Rule 185 (regulations governing case management standards and county responsibilities) specified what case management services are to be provided and minimum standards for how to provide them.

The GCDD thought that, in theory, case management should support families and adults with developmental disabilities. Support should be as unintrusive as possible, easily accessible, and efficient and cost effective. Case management should be rooted in values which enhance individual growth, personal dignity, and inclusion in the social nature of humanity; and be dedicated to basic human and constitutional rights. Above all else, case management should produce positive change in people's lives.

Public testimony in 1985 indicated that, while case management is one of the most critical services, it was seen as one of the weakest. The GCDD decided to focus on case management as its priority for the three year planning cycle 1986-1989. Rather than using the funds for case managers, grant applications were sought for research, improving case management, empowering consumers, and volunteer monitoring.

The GCDD funded 13 projects in the following areas:

- Vouchers for family support.
- Laptop computers for case managers (to reduce paperwork)
- Parents as Case Managers

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- Personal Futures Planning (training and resource development)
- Partners in Policymaking®

Specific project outcomes included:

- Creation of a computer based system for case managers.
- Training of 44 parents to assist case managers.
- Training of 17 persons in the use of personal futures planning.
- Training of 19 volunteers who monitored 11 facilities in seven counties.
- Training of 133 persons as peer advocates.
- Ninety parents and 15 self advocates completed the Partners program.

The development and dissemination of publications by the GCDD kept the issue of reforming the case management system alive. The Minnesota Case Management Study was summarized in a 1988 Policy Analysis Series paper. An earlier paper, *The Case Management Team: Building community connections* was reprinted in 1989. *Case Management: Historical, Current & Future Perspectives* was published in 1989 and *Shaping Case Management in Minnesota* was published in 1991.

The work on personal futures planning that started during this time period has had a lasting impact on how individuals with disabilities and their families plan for the future.

Personal futures planning is a tool for fostering new ways of thinking about people with developmental disabilities. Futures planning helps groups of people focus on opportunities for people with disabilities to develop personal

“Don’t wait for anyone. We need person based data about independence, productivity and integration.”

Fran Smith

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relationships, have positive roles in community life, increase control over their own lives, and develop the skills and abilities to achieve these goals.

It's Never Too Early, It's Never Too Late is a classic publication. Entire agencies are adopting a personal futures planning approach so requests for these materials are increasing.

Changes in the DD Act

In 1984, the DD Act recognized that funds are not for direct services but intended to promote systems change. New language stated the Act’s real purpose – to achieve maximum potential through increased independence, productivity and integration into the community. After 1986, employment related activities would be a mandatory priority in each state.

In 1987, amendments clarified that the purpose of the DD Act is to develop a comprehensive system and coordinated array of services through planning and coordination, building the capacity of public and private nonprofit groups, gathering information, developing model policies and procedures, influencing policymakers, demonstrating new ways of action, and training family members and citizens. More importantly, the DD Act now recognized that families and members of the community could play a central role in the lives of people with developmental disabilities by adding to the purpose statement - “to enhance the role of the family.”

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The 1990s - Leadership, Empowerment and Accountability

A Ten Year Priority

The GCDD took a retrospective look at its work in 1990. William Bronston's report pointed out the limitations of three-year grant strategies, and recommended a ten-year priority and strategy. Experience showed that the greatest payoff involved personal transformation and the pyramid effect - change builds one year to the next.

During the decade of the 1990s, the GCDD's priority was leadership. Grant funds were invested in the development of leadership skills among people with disabilities and their families. Youth and members of minority communities received specific attention. Projects of National Significance funds were used to develop a broader understanding of the concept of self determination and continue efforts to bolster family support. The GCDD's publications continued to give people information about innovative approaches and advocacy tools to effect change. *Minnesotans Speak Out!* (1992 and 1997) amplified the voices of Minnesotans who spoke about what works well in the delivery system, where gaps exist, and where changes could be made.

The 1990 DD Act redefined integration as the use of the "same community resources in living, learning, working and enjoying life," and the development of "friendships and relationships" together with people without disabilities. The purpose of family support services expanded to include strengthening and maintaining the family unit, and preventing inappropriate out of home placements.

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The 1994 DD Act placed greater emphasis on developing the capacities and competencies of individuals, and the purpose was more clearly stated in terms of capacity building and systemic change.

Partners in Policymaking®

A cornerstone of the leadership development strategy has been the Partners in Policymaking program.

Partners in Minnesota

Partners in Policymaking is an innovative national model of leadership training designed for parents of young children with developmental and adults with disabilities. Partners provides state-of-the-art knowledge about disability issues and teaches the leadership skills to become effective advocates in influencing policy at all levels of government.

The program was created in Minnesota in 1987. By 1990, more than 100 graduates were trained on policy issues and advocacy. Their learning clearly evidenced benefits of the program:

- 36 people appeared on television and radio shows.
- 76 people were appointed to state and regional commissions.
- 1,618 letters were written to public officials.
- 946 phone calls were made to public officials.
- 466 visits were made with public officials.
- 41 letters and articles were published.

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“In 1993, Debra Niedfeldt (MN) spoke to Mrs. Clinton and Marcia Callender (NY) spoke to President Clinton about health care issues.”

Both are Partners graduates

The Partners program teaches leadership skills and the process of developing positive partnerships with elected officials and other policymakers who make decisions about services. Documented results show that the program results in increased independence, productivity, integration and inclusion of individuals with disabilities and their families into their communities. Partners graduates become active citizens in the policymaking process at local, state and national levels.

The program consists of three primary components:

- Eight, two-day sessions for a total of 128 hours of leadership training over an eight-month period.
- Readings and homework assignments that supplement and reinforce the knowledge presented and skills taught at each weekend session.
- A public policy project that demonstrates successful application of these leadership skills.

By the year 2000, the Minnesota Partners program had trained just under 550 parents and people with disabilities with impressive results. The GCDD had funded the program consistently for thirteen years, eighteen classes had graduated, and the network of Partners graduates covered 80 of Minnesota's 87 counties.

Partners graduates continue to educate elected officials at local, state, and national levels; and distribute information on current issues. They actively participate in forums and meetings to discuss how services and supports really

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contribute to full community participation and family unity, and ways to improve the system and remove barriers for a more responsive and culturally competent delivery system.

Partners Goes National and International

The GCDD has also received several Projects of National Significance grants from the Administration on Developmental Disabilities to assist other states in replicating the Partners program. In 1990, the GCDD and the World Institute on Disability conducted the first Partners in Policymaking National Academy in California for 12 states. In 1992, the Texas DD Council and the GCDD cosponsored the second Academy for 24 states. In 1993, the third Academy was attended by representatives from 36 states. Additional academies were held in Kentucky in November 1997 and in Manchester, United Kingdom in October 1998.

In 1995, Partners in Policymaking could claim more than 4,000 graduates, each part of a growing national network of community leaders serving on policymaking committees, commissions, and local, state, and national boards. By 1996, 42 states had operated a Partners program, three more states were planning to offer the program, and Partners became operational in Great Britain and the Virgin Islands.

Today, 47 states have replicated the program or offered some type of leadership training. More than 9,000 individuals are part of the international network of Partners graduates.

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Cultural Outreach Programs

Throughout the 1990s, GCDD grants have supported cultural outreach programs in the African American, American Indian, and Hispanic American communities.

In the African American community, small groups of parents began meeting twice a month for leadership training and personal support. Support groups and at-home services were also provided. Over the years, more than 300 African American families have been involved in this effort, at least 80 parents have graduated, and many are now Partners graduates. They have made impressive, concrete changes in their lives. In 1996, for instance, 25 children left out-of-home placements and were reunited with their families.

The cultural outreach programs have expanded to the American Indian and Hispanic communities. Many American Indian families have attended training sessions, some have graduated from the programs, and about 12 parents have gone on to participate in the Partners program.

In 2000, focus groups were held in the American Indian and Hispanic communities where interest was shown for a new Family Support Council.

As part of a subcontract with Oregon Health Sciences University (OHSU) Self Determination Center, four replication meetings were held in 1998 and 1999 for emerging leaders in African American and American Indian communities. As a result, cultural outreach efforts were fostered in 10 states and the District of Columbia.

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Partners Graduate Workshops

Advanced Leadership training is made available to Partners graduates to expand and improve their personal leadership skills and strengthen the Partners network. On an annual basis, approximately 30 Minnesota Partners graduates have been supported to attend conferences and workshops that continue to increase their skills and knowledge. This includes five national Summer Leadership Institutes as well as other opportunities within the state.

Youth Leadership

During the 1990s, the GCDD supported a number of initiatives to teach and improve the leadership skills of young people with and without disabilities. The projects involved a value based approach, raised awareness of social justice issues, and promoted inclusion.

Approximately 24 students (equal numbers of students with and without disabilities) participated each year in the Youth in Government program, a model program for young adults that offers practical learning experiences on how the three branches of state government work. One student with a disability became the GCDD's representative on the state Transition Leadership Committee.

Approximately 70 students each year participated in Service Treks, an outdoor camping and service learning experience. This four-day program, using an "outward bound" approach, challenged youth with and without disabilities to

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reach beyond their current comfort levels, and learn more about their capabilities and the world around them.

The GCDD also supported the development of a Youth Leadership curriculum that is being replicated throughout the YMCA in other states. The curriculum is a hands-on guide for creating a youth leadership program, building on the need for young adults to identify with peer groups, develop positive friendships, and serve their community. Through participation in the Youth Leadership program in Minnesota, students have maintained friendships with their peers throughout middle school and into their high school years. Some schools are now accepting community service, performed through the Youth Leadership program, as credit toward high school graduation.

Advocacy Tools and Contexts

Over the years, the GCDD has produced or supported the production of three types of tools for advocates:

- **General guides for advocacy and social change work.** In 1989, a community organizing manual, *Action, This Means War!*, was developed. In 1994, *Making Your Case* updated this publication by drawing on the perspectives of legislators in terms of what works to influence public policy change and understanding the process.
- **Checklists related to specific issues and situations.** From 1987 to 1993, the GCDD developed checklists for quality individual plans, individual education plans, school integration, and family support. *Read My Lips*, a resource guide of activities and checklists using a person centered

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planning approach, looked at five ways of helping to increase the freedom of choice for people with developmental disabilities.

In 2001, this guide was revised, updated, and titled *It's My Choice*.

- Specific guides to influence change on specific issues. The GCDD developed information packets on the Medical Assistance Prior Authorization Program, Rehabilitation Act Reauthorization, the Early Childhood Special Education Program, and Family Support. The *Action, This Means War!* Manual was used for passage of Medicaid reform measures and the Americans with Disabilities Act.

In 1992, the Deputy Commissioner of the Department of Human Services appointed a study group to “review the current structure under which developmental disabilities services are provided and to review costs.” The study group sought input from Minnesotans through a series of town meetings. The town meeting results are contained in the 1992 edition of *Minnesotans Speak Out!*; a second edition followed in 1997.

Training Conferences

The GCDD has cosponsored training conferences organized by various state and regional groups and organizations. Each year, between 1,000 and 1,500 family members and individuals with developmental disabilities attend conferences that focus on leadership training and leadership development.

Projects of National Significance - Self Determination and Family Support

In the early 1990s, the GCDD received grant funds for a self determination project. A national survey on self determination was conducted and a panel of 25 experts involved in community organizing and empowerment was convened. Two Summer Leadership Institutes for Partners graduates were held and focused on self determination. A briefing book and videotape, *Shifting Patterns*, were developed and focused on individual and family self determination. In 2000, the DD Act was reauthorized and self determination was added as an outcome.

The Family Support project between 1992 and 1994 created resources about family support and developed a constituency for change among families, people with disabilities, and state governments. Twenty-six states signed on to national family support legislation and a national repository for family support resources was developed.

MAKING A DIFFERENCE IN THE FUTURE

The New Century

The GCDD's strategies for 2001 to 2006 carry on the momentum that began in the 1990s with the Leadership priority.

PARTNERS IN POLICYMAKING

- Partners in Policymaking, a leadership training program designed for adults with disabilities and parents of young children with developmental disabilities, will be held annually.
- Workshops for Partners graduates will be offered to strengthen personal leadership skills. Topics may include negotiation skills, facilitation skills, and grant writing.
- Longitudinal studies of Partners graduates will be conducted annually.
- Cultural outreach programs will be conducted annually in the African American, American Indian, and Hispanic communities for parents of children with developmental disabilities.
- A pilot program, Partners in Policymaking for Employers, will be tested with Minnesota businesses aligned with the Baldrige framework.
- Self advocacy will be supported and strengthened.

COMMUNICATIONS AND TRAINING

- Publications and resource materials will be available free of charge in accessible formats.
- All products and services will be converted to web accessible formats in accordance with Electronic Government Services (EGS) objectives.
- Training conferences will be cosponsored annually.

CUSTOMER FOCUS AND QUALITY IMPROVEMENT

- Customer research will be conducted on customer needs, requirements, and expectations. Customer satisfaction data will be collected systematically.
- The GCDD and suppliers will increase their knowledge, understanding, and application of the Baldrige framework.

“Our county now has family support because I brought the information back from my Partners in Policymaking experience.”

Partners Graduate

COUNCIL MEMBERS

Maribeth Ahrens	Sandra Fink	Robert Jirik	Mary O'Hara	Ernie Sibernagel
Jeffrey Alexander	Bonnie Ford	Byron Johnson	Anderson	Ed Skarnulis
Richard Amado	Lois Fort	Karol Johnson	Paul Odland	Jeffrey Skwarek
Dawn Anderson	Eugene Frey	Paula Johnson	Chet Oden	Bonnie Jean Smith
Will Antell	Mary Fox Sinclair	Robert A. Johnson	Nancy Okinow	Susan Shogren
Catherine Atneosen	Mary Rae Freeberg	Michal Jorgens	Marijo Olson	Smith
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Ellen Fifer	Jan Jernell	Cynthia Obinger	Duane Shimpach	

This list of past and present council members was compiled from council archives.

We deeply appreciate all their efforts and we honor the memory of those who have died.

We sincerely apologize for any errors.

Additional reports are available through GCDD.

Alternative formats are available upon request.

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