Self Determination & Consumer Directed Community Supports (CDCS) – Minnesota 1990-2006

There have been a number of revolutions in the ways we think about people with developmental disabilities and organize resources and supports available to them.

- CITIZENSHIP. One has been a civil rights victory – the recognition in law and practice that people with disabilities are citizens in the fullest sense of the word, with the rights and accompanying responsibilities of citizenship.
- MEMBERSHIP. Another revolution has been the recognition, in values and action, that people with developmental disabilities belong in community, amidst family and friends, neighbors, classmates, work colleagues; spending time in the many places of our communities with other members of the community.
- SELF DETERMINATION. A third revolution has been the development of ways to recognize the right and ability of people with developmental disabilities, often with the support of family, friends and other allies, to make decisions about their lives.

The concept of self determination and its application in Minnesota emerged in the context of national trends and developments. Minnesotans were an integral part of these developments, exercising leadership; seizing opportunities; and resisting funding cuts.

1. National Developments

The **Independent Living Movement** was the strongest early voice calling for people with disabilities to enjoy the rights and responsibilities of citizenship, participate in and contribute to the life of the community, have access to the opportunities and resources of community, and make decisions about their own lives.

Some of the key principles of the IL movement were:

- Living like everyone by attaining skills and receiving supports, controlled by each individual.
- Peer support through the use of role models who mentor and provide individualized coaching that will enhance quality of life issues and ways to contribute in our communities.
- Having the right and opportunity to pursue a course of action, limited only in the same way that one’s neighbors without disabilities are limited.
- Having opportunities to make decisions that affect one’s life.
- Having the freedom to fail and to learn from one’s own failure, just as people without disabilities do.
- Having the right and opportunity to be a self advocate and systems change advocate at the local, state and national levels.

In the late 1960s and early 1970s, Centers for Independent Living emerged for people with physical disabilities. Activists like Ed Roberts (http://www.mnddc.org/ed-roberts/) in California had a lasting impact on the lives of countless generations. The idea took hold that people with disabilities are fundamentally capable and able to take on the rights and responsibilities of citizenship, contribute to the life of the community, take control of their own lives, and like everybody else, do so with the assistance of friends and allies.

Advocates from the Independent Living Movement and the community of people concerned with the lives and futures of people with developmental disabilities achieved major gains in **Federal legislation and policy** that recognized and enabled the civil rights of people with disabilities, and increased the resources available for community living. There were repeated amendments to the Rehabilitation Act, and the passage of the Developmental Disabilities Bill of Rights Act and the Education of All Handicapped Children Act. The 1978 and 1983 amendments to the Rehabilitation Act created comprehensive services for Independent Living, funding for Centers for Independent Living, and the Client Assistance Project.

The 1980s

In 1981, the federal government created Title XIX Home and Community-Based Services (HCBS) Programs. Up until that time, many of the community supports and services intended for people with disabilities such as respite care, attendant care, and assistive services, were not covered by the regular federal Medicaid program. Federal Medicaid rules allowed states to use federal Medicaid funds for institutional services. The HCBS waivers gave states the federal approval necessary to waive specified Medicaid rules and use Medicaid funds for community supports and services. The Centers for Medicare and Medicaid Services (CMS) (formerly the Health Care Financing Administration) requires that the cost of services paid through HCBS waivers be less than or equal to, on average, the cost of serving people in institutions. Medicaid programs are financed by state and federal governments. The federal government matches the state dollars spent on approved programs.

The recognition of civil rights and the development of mechanisms for using federal funds for community support laid the groundwork for many of the changes that were achieved over the next three decades.

In the 1980s the **voices in the movement for inclusion** became stronger on a number of dimensions. Beth Mount, John O'Brien, and Connie Lyle, among many others, articulated a perspective on person centered planning, and the essential outcomes or accomplishments that are truly important for people with disabilities. The People First and Self Advocacy movement spoke out on rights issues, including the right to a voice in decision making, and to be heard as a person not a label. The Minnesota Governor's Council on Developmental Disabilities (DD Council) , in 1987, introduced the *Partners in Policymaking* training curriculum which became a national and international force assisting people with disabilities and family members to empower themselves to determine their own futures and work with policymakers to shape public policy in support of self-determination.

O'Brien described Five Essential Accomplishments that would enable people with disabilities to enjoy life experiences valued by all members of the community. Those accomplishments are:

- Community Presence
- Community Participation
- Valued Social Roles
- Choice
- Contribution.

These translate into a series of questions to guide the work of change agents and supporters:

- COMMUNITY PRESENCE: How can we increase the presence of a person in local community life?
- COMMUNITY PARTICIPATION: How can we expand and deepen people's relationships?
- ENCOURAGING VALUED SOCIAL ROLES: How can we enhance the reputation people have and increase the number of valued ways people can contribute?
- PROMOTING CHOICE: How can we help people have more control and choice in life?
- SUPPORTING CONTRIBUTION: How can we assist people to develop more competencies?

Self advocates and their allies called for the right and resources to choose where and with whom they lived, to get an education, to have a real job that pays a real wage, and to take advantage of the opportunities available to other members of the community. Families called for resources and power that would allow them to support their family members with disabilities to get the kind of support they need, and be able to live in the community rather than in institutions and other environments that kept the apart from the rest of society.

These perspectives and demands laid the groundwork for numerous changes in public policy and approaches within the service system.

Initially, having choice and the power of decision making meant advocating for real choices other than institutionalization. As community services began to develop, ever so gradually, choice and determination meant choosing from a limited array of funded services. Choice was exercised in the context of individual program planning – processes whereby individuals and families were given opportunities within the existing programs of the services in which they participated. Agencies received funds from government to operate programs to which individuals were admitted. Over time, those programs were individualized to the extent that they were able to tailor what they offered to the needs of each individual. This often led to minor adaptations to what was offered.

A growing understanding of what Person Centered Planning could mean in terms of shaping action and the development of supports in response to the person meant that individuals and families began to plan on their own, then approached services for the supports they needed. Services and opportunities began to respond to "consumer demand". New programs were developed in response to new demands. The case management and planning approaches developed in the context of some court ordered institutional closures provided a great deal of experience in planning services and supports for individuals, rather than simply channeling those individuals into existing beds and slots.

In these early decades, the concept of Self Determination was quite broad. It has to do with making choices and having a decisive voice in decisions about one's own life. The central people in making choices and decisions included the individual, parents or guardians, and eventually a broader network of circle of friends and family.

A component of Self Determination had always been having control over the resources, especially funding, which would support people to act on their choices and realize their dreams.

With time, having control over funding and services became the central characteristic of discussions about Self Determination.

The 1990s

In the 1990s, Thomas Nerney and others developed a set of principles and perspectives that were the underpinning for self determination efforts across the country. The focus was on how the principles of self-determination could be applied to organize and deliver supports "beyond managed care". They defined self-determination in terms of an attempt to fundamentally reform both financing mechanisms and basic structural aspects of the service delivery system.

- **FREEDOM – The ability for individuals with freely chosen family and/or friends to plan a life with necessary support rather than purchase a program**. Operationally, this means that people with disabilities will have to option of utilizing public dollars to build a life rather than purchase a pre-determined program. Freedom means that individuals with disabilities, within some rational and cost-efficient system, will be able to control resources via individual budgets in order to gain the necessary experience in living and to move the dollars when their life choices change.
- **AUTHORITY – the ability for a person with a disability (with a social network or circle if needed) to control resources, both informal and formal, that will assist them to live a life they choose**. Operationally, this means that individuals with disabilities really do have meaningful control over some limited amount of dollars to purchase the supports they need. Realistically, many people need assistance to control dollars and planning.
- **SUPPORT – the arranging of resources and personnel, both formal and informal, that will assist an individual with a disability to live a life he or she chooses, in the community and rich in association and contribution.** Operationally, this means assisting the individual to develop at support network of family and friends; to take advantage of opportunities throughout the community, not just within services; and draw on both paid support and natural relationships.
- **RESPONSIBILITY – the acceptance by the individual (and the social network) of the benefits and risks for decisions made, and accountability for spending public money in ways that assure health and safety and that are life enhancing.** Operationally, this

> means the development of individual budgets that can be used to build the supports a person needs by purchasing only what is needed and paying only for what is received. It means the involvement of caring social networks and the support of individual brokers who can assist in identifying and arranging necessary supports.

In part, self determination requires significant policy changes to enable individuals and families to identify their own needs, marshal the resources required to meet them, control the use of those resources, and determine whether or not they are working. For this reason, much of the focus on self-determination became concerned with systems management and policy change. From that perspective, self determination is a means by which individuals who are eligible for state developmental disabilities services are empowered to gain control over the selection or services or supports, that meet their needs. The principles and values embodied in self determination are implemented through new configurations of services and supports in combination with existing services. When individuals want to participate in community opportunities outside the state service delivery system, they can allocate funds from their personal budgets to support that involvement.

A number of national developments supported efforts by states and communities to operationalize these principles and the ability of individuals with disabilities to be more in control of their lives and futures.

The Robert Wood Johnson Foundation launched a national program – the National Office of Self Determination for Persons with Developmental Disabilities. In its call for proposals, the RWJ program presented Self Determination in the following context:

> Self-determination is an important next step allowing persons and their families and friends, in conjunction with professionals, to be the decision makers concerning the supports that are needed and how they best can be provided, The most innovative self-determination initiatives… are those in which persons and families have the chance to determine how an individual budget will be spent on housing, employment and personal needs….
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> This national program offers an approach for states to improve the efficiency and effectiveness of their human service systems… Many observers suggest that the high cost of the present system is due in part to the one-size fits all uniform standard of care that results in an unnecessarily expensive system. In contrast, self-determination allows individuals to purchase only what they need.

The RWJ project recognized that states were adopting managed health care in their Medicaid programs to control the cost of primary and acute health care, and that there was growing interest in applying managed care concepts to long term care. The Self-Determination Project hoped to demonstrate how resources and supports could support people with developmental disabilities in a more creative way. In 1997, the RWJ Foundation awards grants to 18 states, including Minnesota, to further the self determination initiative.

Also in the 1990s, The ARC United States began to examine and support self-determination. Initially, it conducted a series of projects funded by the U.S. Department of Education, then established "The Arc's Self-Determination Program" in 1996 to conduct model demonstration, outreach, and research projects; provide technical support and disseminate information; and advocate with individuals and families to promote opportunities for self-determination and choice.

At the same time, Title XIX Home and Community-Based Services Program waiver options were being used to develop Consumer-Directed Community Supports. In 1993, the Omnibus Budget Reconciliation Act of 1993 added a section to the Social Security Act formally recognizing that states could offer personal care services under their state Medicaid plans. National and nation-wide concerns about the costs of Medicaid and long term care were providing the context for examining how managed care might be reformed to allow for more individualization and self determination. States had to get a waiver from CMS in order to be granted authority to capitate Medicaid payments which would help maximize individual choice and responsibility in planning services and supports.

Minnesota was one of the pioneering jurisdictions in this area. In October 1989, Dakota County and the DD Council initiated the Dakota County Voucher Project (which later became known as the Account Management Project. It was one of the first efforts in the country to test the feasibility of families arranging for, locating and managing their own service networks using country funds. Families were empowered to allocate funds in approved support areas. Families hired their own support providers. Similarly, in Michigan, the Department of Social Services operated a Home Help Service Provide program which enabled families to select and employ their own home help service providers consistent with a service plan and attached state funds.

In 1997, Minnesota was among the first states to receive to receive a grant from the Robert Wood Johnson Foundation's Self-Determination initiative.

Such initiatives paved the way for projects across the country and the federal policy and legislation to enable them.

In 1999, the Olmstead decision had a profound impact on the growth of consumer directed community services. In Olmstead v. L.C., the Supreme Court affirmed the right of individuals with disabilities to receive public benefits and services in the most integrated setting appropriate to their needs. The decision interpreted Title II of the American with Disabilities Act (ADA) and its implementing regulations. Medicaid can be an important resource to assist states in fulfilling their obligations under ADA. The HCBS waiver program in particular is a viable option for states to use to provide integrated community-based long-term care services and supports to qualified Medicaid eligible recipients.

In the wake of Olmstead, the CMS made it clear that consumer directed personal care services could be furnished to people with developmental disabilities. The personal care services could be provided as part of a Medicaid state plan service, and also as part of home and community-based waiver programs.

> Consumer-Directed Services - A State may employ a consumer-directed service delivery model to provide personal care services under the personal care optional benefit to individuals in need of personal assistance, including persons with cognitive impairments, who have the ability and desire to manage their own care. In such cases, the Medicaid beneficiary may hire their own provider, train the provider according to personal preferences, supervise and direct the provision of personal care services and, if necessary, fire the provider. The State Medicaid Agency maintains responsibility for ensuring the provider meets State provider qualifications ... and for monitoring service delivery. Where an individual does not have the ability or desire to manage their own care, the State may either provide personal care services without consumer direction or may permit family members or other individuals to direct the provider on behalf of the individual receiving services.

2. Developments in Minnesota to 2006

The 1980s

Minnesotans played a major role in the early development of an understanding of self-determination, and consumer directed services.

In 1984, Minnesota began implementing the Title XIX Home and Community based Services waiver. At that time, Minnesota had the highest per capita ICF/MR capacity in the nation. The nature of DD services, however, had come under close scrutiny, especially in the context of the Welsch class action law suit. Conditions in the Welsch settlement included developing appropriate community-based services using mechanisms such as the waiver. As a result, the state, counties and communities developed and expanded community based options, but also provided people with disabilities and their families with growing experience in the limitations of a system based on limited choices of programs and services provided by a limited number of service providers.

In 1987, the DD Council initiated *Partners in Policymaking* to teach parents and self-advocates the power of advocacy to change the way people with disabilities are supported, viewed, taught, live and work. During the first two decades of *Partners*, important issues were confronted and dramatic changes have been made. Since 1987, over 21,000 people have graduated from the program.

The 1990s

In October 1989, Dakota County and the DD Council initiated the Dakota County Voucher Project, later known at the Account Management Project. The project tested the feasibility of families arranging for, locating and managing their own service networks using country funds. Families were empowered to allocate funds in approved support areas. Families hired their own support providers. As one social worker observed at the time,

> Families, and many of us working for services for families, were becoming increasingly frustrated by bureaucratic regulations and shortages of resources. Government ideology that it knows what families need better than the family was an additional concern.

The Dakota County project informed the development of the proposal in July 1996 from the Minnesota Department of Human Services to the Robert Wood Johnson Foundation requesting a three year grant of Self-Determination for Minnesotans with Developmental Disabilities.

That proposal was linked to efforts to apply managed care reforms to services for people with developmental disabilities.

> Minnesota, like other states, is using managed care models to address the problem of financial deficits or reductions at the state and federal level and to control increases in health care expenditures. Minnesota has expanded its use of managed care for the acute care needs of persons eligible for Medicaid because they are AFDC recipients, but has little experience with managed care for the acute and continuing care needs of persons with disabilities. This issue is especially important because approximately 42% of Minnesota's total Medicaid budget of $3.1 million is spent on persons with disabilities, and Minnesota spends $600 million annually in providing medical, social, and long-term care services and supports for over 21,000 persons with developmental disabilities. Since almost 80% of those dollars go towards long-term services and supports, restructuring how these services and supports are provided will need to be part of any solution to the current state and federal budget problems. The question becomes how Minnesota can extend managed care models to long-term care service and supports without significantly restricting *access* to services, limiting individual choice, or reducing quality of service. Minnesota believes that self-determination approaches to long-term care services and supports will help increase service access, consumer choice and control, and the quality of services and supports while helping us to control the rising costs of those services and supports.

In 1995, the Minnesota Legislature authorized the Department of Human Services (DHS) to develop two pilot projects to test managed care reform of services for people with developmental disabilities. The Demonstration Project for People with Disabilities identified two project sites: The Southern Minnesota Health Initiative-Blue Earth County and Project Foresight-Olmstead County. The DD Waiver Allocation Structure Advisory Committee was formed to guide the Department of Human Service's activities in managed care reform. The Demonstration Project was intended to develop and evaluate a coordinated service delivery system for individuals with developmental, mental health and physical disabilities. Initially, the project sites were to serve persons with developmental disabilities, but the 1997 Legislature authorized expanding the projects to serve all individuals who were eligible for Medicaid and disabled living in the two sites. The Department of Human Services began to plan the projects, applied for the Medicaid waiver which would allow the projects to proceed and for Medicaid payments to be capitated.

The Robert Woods Johnson Foundation proposal was developed in this context. In early 1997 the RWJ Foundation awarded grants to 18 states. Minnesota was one of the nine states to receive a three year grant. The DHS provided in-kind contributions to the Foundation's financial support and a federal dollar match became available through an amendment to the waiver plan. The core of the project was to ensure comprehensive, community supports.

> By comprehensive, it is meant that programs include person-centered planning; individually-controlled budgets; consumer-controlled housing; outcome-based quality assurance and quality improvement assistance; consumer education and support; and consumer and family choice of providers, support staff, and, as appropriate, the type and amount of support.

In December 1997, the DHS received approval to add a “Community Based Community Supports” option to its DD waiver program. The Consumer Supported Grant Program was initiated.

> The grant is intended to replace services the consumer is currently receiving such as homemaker, personal care attendant, and home health aid services. Typically the consumer, using grant funds, can purchase these types of services for a lower cost from people they know and trust. Consumers participating in CSG will have the flexibility to choose the provider they want and control over how the services are provided. Service providers can be family members, neighbors, friends, or anyone the consumer chooses. Participation in the program is voluntary on the part of both the consumer and the county….

Starting in 1998, the MN Self Determination Project (funded by the RWJ Foundation grant) launched the Consumer-Directed Community Supports in Blue Earth, Dakota, and Olmstead Counties. The counties received a three year grant.

In July 1998, the DHS received federal approval to serve additional waiver recipients without using additional funding. County agencies that did not use their allowable waiver resources were able to optimize services using available funds to serve people who have been waiting for waivered services. Reports of spending throughout Minnesota had shown that waiver funds were being underspent.

At the same time, State Medicaid Directors also received a letter from the U.S. Department of Health and Human Services outlining court decisions in three jurisdictions (including the *Olmstead* case). The director of the Center for Medicaid and State Operations informed states that the Attorney General has indicated that, under the ADA, States have an obligation to provide services to people with disabilities in the most integrated setting appropriate to their needs…. The Department of Justice recently reiterated that ADA’s ‘most integrated setting’ standard applies to States, including State Medicaid programs.” The

Director urged States to meet the objectives of the ADA my continuing to develop home and community-based service options for persons with disabilities to live in integrated settings.

In 1998, the DHS issued a call for proposals to evaluate the Medicaid HCBS waiver program in Minnesota. In 1999, the Research and Training Center on Community Living (RRTC) at the Institute on Community Integration (University of Minnesota), in collaboration with Arc-Minnesota and its local affiliates, received a nine-month, $100,000 grant from DHS to conduct the evaluation.

In 1999 the MN Legislature created several ways by which the waiting list for DD Waiver services could be decreased. It directed the DHS to eliminate or reduce the size of the waiting list for waiver services. The DHS redesigned the DD Screening Document to assess the urgency or time frame in which waivered services were needed. Then in 2000, the Legislature passed law MN Stat.256B.0916 which required the DHS to seek federal approval to extend the Consumer-Directed Community Supports option in the DD Waiver statewide and ensure that such services would be in place by January 2002. In an effort the streamline the system, DHS decided to use the waiver request to make the option available to all disability and elderly waivered service programs.

2000 and Beyond

As the new approach to Consumer-Directed Services, concerns were raised by organizations such as the MN Disability Law Center about the extent to which some groups and services might be excluded from the program, whether or not family members would be allowed to receive payment as caregivers, and the ability of parents to direct Medicaid payments received for their children. One of the issues was the Medicaid requirement that the waivers be budget neutral. The DHS expansion of the waiver might result in large numbers of families “coming out of the woodwork” seeking services and supports.

In this context, there were several forces working on the development of consumer directed services. Those forces are outlined in a statement from DHS to the counties about adding new clients to waivered services.

> The county is not obligated to provide waivered services to all eligible people on its waiting list. The county must, however, provide all medically necessary services to current recipients to assure that their health, safety, and welfare needs are met. Counties must also assist the state in complying with its obligations under the Americans with Disabilities Act and the Olmstead decision to avoid unnecessary institutionalization by providing services in the most integrated settings appropriate for consumers. Therefore, it is critical that each county make decisions about the feasibility of adding new recipients both on the basis of current and anticipated needs of consumers balanced against the urgent need of those who are waiting for services.

Throughout this period, the Office for Civil Rights and CMS, U.S. Department of Health and Human Services, were issuing updates about the implications of the Olmstead decision on services for people with disabilities, and increasing the pressure for expanded home and community based services in the least restrictive environment. In July 2000, the last resident with developmental disabilities left the Regional Treatment Centers in Minnesota.

By December 2000, the DHS had agreements with six counties and one partnership of five counties to provide consumer directed support services. Many people were waiting for all kinds of home and community based waiver services, especially assistive technology, environmental modifications, in-home family support, respite and supportive living services.

In 2001, the DHS opened enrollment to all eligible persons for a three-month period. This resulted in about a fifty percent increase in the DD Waiver program. Shortly after this enrollment surge, the state's budget situation deteriorated. The DHS also issued a manual for county agency staff to help them implement consumer directed supports and understand their responsibilities.

Advocacy organizations at that time were concerned about the unspent funds in county budgets and the waiting list crisis. There were signs of hope from the opening of enrolment, the establishment of the Family Support and Personal Care Assistance programs, and the expansion of the Consumer-Directed Community Supports statewide. The DHS was eventually awarded a three-year federal Systems Change grant from the Centers for Medicare and Medicaid Services (CMS) to focus on Consumer Directed Personal Assistance Services and Supports previously known as the Consumer Support Grant Demonstration Project 1115 waiver proposal.

In 2002, two major developments emerged. Both continued over several years. The first development was DHS changes to the Consumer Directs Support Program. The second development was a series of major cuts to the budget for waivered services, including Consumer Directed Support.

<u>The proposed plan amendments to the Consumer Directed Support Program developed by the DHS were seen by advocacy organization as threatening the very substance of the program</u> -- Will the CDCS consumer have input on budget development? Will the CDCS consumer design the scope of the services needed? Will the CDCS consumer determine who will provide service? The flexibility and range of choices present in the initial phases of CDCS that led to high level of consumer satisfaction were seen as being eroded. The Minnesota request for the waiver amendments was submitted in September 2002 . Then additional amendments were requested in 2003 and concerns continued into 2004.

Focus groups sponsored by the DHS and a survey sponsored by the DD Council both indicated frustrations with the CDCS program based on the gap between the program's promises and what was being delivered. Recommendations were put forward to deal with those frustrations. Proposed amendments by the Department, however, were not seen as consistent with what was recommended.

One County's response to the proposed amendments in 2004 identified the following ways in which the amendment failed to support the achievement of the consumer outcomes for which the program was designed:

- Rather than maintaining the ability of the individual to remain in the community, it [the amendment] diminishes resources to a point where families of high needs recipients, particularly adult recipients, will be unable to care for their family members in their homes. It rewards segregated services and promotes a return to more institutional living arrangements.

- Rather than enhancing community inclusion and family involvement, it restricts access to community environment and pushes families to request placement due to inadequate support resources in the home..
- Rather than developing or maintain personal, social, physical, or work related skills, the amendment severely restricts this by disallowing memberships, tickets, and reimbursement for related community training and expense.
- Rather than decreasing dependency on formal support services, the budget setting methodology provides incentives to remain in or return to formal services.
- Rather than increasing independence of the individual, it decreased opportunities by disallowing supported opportunities for training in a multitude of community environments.
- Rather than increasing the ability of unpaid family members and friends to receive training and education needed to provide support, it decrease their ability by disallowing reimbursement for travel, lodging and meal related to training...

.... Overall there is a significant disconnect between two of the stated goals of CDCS and the implementation of details:

  - Creating a very flexible option that supports the policy of consumer control and tailoring of services to meet individual circumstances.
  - Establishing checks and balances, which provide accountability and effective management of public funds.

<u>The second major development starting in 2002 and continuing until 2004 was the budget</u>. There were clear signs of substantial cuts to state funds available to all waiver programs which began to be implemented in concrete actions by the Governor and the Department of Human Services in 2003. This resulted in numerous advocacy efforts throughout 2003 and 2004.

Eventually **two class action law suits** in an effort to halt the DHS rebasing funds allocated to counties for Home and Community-Based Waiver Services. A temporary restraining order was issued halting the further implementation of rebasing until the court issues a decision. Some counties tried to mitigate the impact of the budget cuts.

> The lawsuit, filed by the Association of Residential Resources in Minnesota and the mother of an 11-year-old youngster with disabilities who was denied services, alleges the agency [the Department of Human Services] failed to comply with federal mandates that compel states to provide such services as an alternative to institutionalization. It also contends the agency's action was based on improper and insufficient data.

The lawsuits were not settled until 2004. In the settlement of the suit brought by the Arc and an individual (Masterman et. al. v. Goodno...), the DHS agreed to increase county allocations and establish a new funding method for waiver services. The settlement also required notifications and obligations when proposing amendments to Individual Service Plans and/or service recipients' budgets and considerations when deciding to add new recipients to the waiver programs. In the settlement of the suit brought by the Association of Residential Resources and an individual (ARRM and Mary Rodenberg-Roberts v. Goodno et.al.) Counties could not place across the board caps on service levels. The MN DHS would establish a new funding method for waiver.

In June 2003, the MN Legislative Audit Commission directed the Office of Legislative Auditor to evaluate the Medicaid Home and Community-Based Waiver programs, in particular the waiver for person with mental retardation or related conditions. The report submitted in February 2004 found lack of sufficient controls over the CDCS program.

In March 2004, the DHS announced that the Centers for Medicare and Medicaid Services (CMS) had approved Minnesota's request to amend the Long Term Care Waivers and the DD Waiver, to provide Consumer Directed Community Support (CDCS) services within each of the waiver programs. In September and October 2004, the Department announced the implementation of the major changes in the program.

> DHS is in the process of developing the elements necessary to implement CDCS, as approved by CMS, across all waivers and in all counties by April 1, 2005. There are two phases in the CDCS implementation plan.
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> The first phase involves the thirty-seven counties that are currently authorized to provide CDCS under the DD waiver. Based on feedback from a recent Legislative Auditor's Report on the waiver programs, DHS will begin implementing CDCS across all waivers in the thirty-seven counties that are currently authorized to provide CDCS under the DD waiver effective October 1, 2004. This initial implementation phase will include transitioning individuals who are currently receiving CDCS under the DD waiver to the new policies, as well as implementation of CDCS across all waiver programs, MnDHO and MSHO.
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> The second phase of implementation will involve the remaining fifty counties and, for EW, interested tribal health entities. These agencies will begin to implement CDCS across all waiver programs, MnDHO and MSHO by April 1, 2005.
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> Beginning with the first phase of implementation, an independent evaluation of the modified policies and procedures will occur. The resulting recommendations will be considered before the second phase of implementation begins.

Specific changes included:

- State-level oversight of CDCS,
- The state sets the CDCS budgets with administration continuing at the county level.
- Many families see dramatic cuts in their DD CDCS budgets and changes in expenditure options.

- Consumers are given the option of dropping DD CDCS and returning to traditional waiver services.
- CDCS is eliminated as an option for people living in licensed residential settings.
- CDCS services are not available to an individual if the Primary Care Utilization Review has at any time restricted the individual or their representative.
- If a CDCS recipient exits the waiver more than once during the recipient's service plan year the recipient is ineligible for CDCS for the remainder of that service plan year.

The concerns raised by advocacy organizations with proposed changes prior to this announcement continued with the final plans. The MN Disability Law Center represented some of those concerns in its letter to the DHS.

> As we learn more about the DD waiver CDCS budget methodology used by DHS to establish budgets for about 2,400 current CDCS participants, we have become increasingly concerned about very significant problems with the implementation of the methodology. We know that the process of developing a budget methodology for CDCS has been very challenging. We appreciate the changes you have made during the summer and in October based on information from counties, families and our office. However, we believe that the methodology is so flawed that its underlying purpose of providing equity to persons with similar needs will not be accomplished. As you will see, we ask that you freeze individual budgets at current levels for those because of the depth and scope of the problems.

Advocacy organizations and families were concerned about the cuts to their budgets and the appeals process. Their concerns and discussions with the Department of Human Services continued into 2005.

The independent evaluation was a 16 month study to end in January 2006, It was commissioned (1) to assess the first-year implementation of the CDCS waiver amendment policies and their initial impacts on county staff, Fiscal Support Entities, and consumers, and (2) to provide evaluation results and recommendations to all stakeholder groups to guide decisions regarding CDCS improvement and expansion. In its summary of the March 2005 report to the Legislature the evaluators stated

> We believed the CDCS to be a worthy, complex service with the potential to significantly benefit consumers. We noted the history of concerns that had been expressed from consumers, county staff, and the Legislative Auditor's Office, The main issue of concern at the time of our report seemed was the statewide budget methodology for determining individual budgets. We encouraged the Department to improve their methodology to the extent possible prior to the scheduled statewide expansion of CDCS.

The 2004 Legislature expressed its concern about CDCS. In *Minnesota Laws 2004, Chapter 288, Article 3, Sec. 32* the Legislature required the DHS to provide the legislature with an update regarding its efforts to monitor the following:

1. Whether any current consumer-directed option participants will have their funding reduced so significantly that their health, safety, and welfare at home will be jeopardized;
2. Whether replacement services will cost more or be of lower quality than their current consumer directed services.

The specific requirement, however, required only an update on the independent evaluation.

In the opening months of 2005, the DHS had been preparing for a number of eventualities, including removing the Consumer Directed Community Supports from all five waiver programs. This was not an option the DHS wanted to pursue, but felt it had to prepare for that eventuality. (2005-08) The MR/RC CDCS Budget Methodology Workgroup worked from January to April 2005 to analyze the Department's formula for setting DD CDCS budgets and if necessary develop an alternative approach. The Workgroup made a number of recommendations to improve the process and maintain the strengths of the Consumer Directed supports. In response, the DHS agreed to publish a Request for Proposals in the fall of 2005 to develop and recommend a new budget methodology; make recommendations for the expansion of CDCS to others in the waiver programs; and identify any and all costs to the state and analyze the impacts on individual county budgets for these waivers. But the existing CDCS language would remain in force until the work was completed.

At the same time, The Arc Minnesota and the MN Disability Law Center were working to change various aspects of the CDCS program. The cuts to the budget resulted in cuts of 50% or more for some families which would take effect by the end of 2005. One of the changes to the Consumer Directed Community Supports would replace in-home supports provided by individuals hired by the individual and family with workers employed by licenses service agencies. Concerns were raised that this would mean that individuals and families would lose control over who shows up to provide care. Dollars that were spent efficiently and used directly to support individuals would be redirected into a restrictive, over-regulated, and administratively costly system. It would mean fewer hours of support for the same money.

In March 2005, the evaluation of the CDCS program submitted its required report to the Legislature. It noted:

> … the DHS reports that enrollment in CDCS has declined by 687 persons since December of 2003, after growing for five straight years. The primary reason for *involuntary* departure (as cited in the county survey) since the amendments' approval was the new eligibility requirements, which restrict CDCS to persons living in their own homes. Few individuals were exited due to immediate health and safety concerns, maltreatment, or suspected fraud. The primary reasons for *voluntary* departure were the comparative ease of obtaining the same or similar services on the waiver without CDCS, insufficient funds in the CDCS budget to sustain needed supports, and higher service authorizations available from the waiver if not in DCCS.

As a result of cuts and changes, many participants were considering returning to traditional licensed services as the only way to maintain their current level of funding. Others filed appeals based on DHS's budget methodology. Families and service providers testified before the Senate Health and Human Services Committee about the impact of cuts (2005-17). The efforts of the Arc and the Disability Law Center were successful to the extent that people could remain on CDCS if they could show that their staffing costs would be the same or less under CDCS, using their 2004 budget allocations. The changes, however, were dependent on the federal government (CMS) approving the language of the amendment, and that approval was not anticipated until the end of 2005 or early 2006.

In August and September 2005, the DHS announced a number of budget increases and changes to its community program supports, including a 5% increase to certain home health agency services, and a 2.2553% increase to the Community Alternative Care, Community Alternatives for Disabled Individuals, DD, and Traumatic Brain Injury waiver programs, including the Consumer Directed Community Supports program.

In September, the DHS submitted its request for amendments to the federal government. The amendments with clarifications were subsequently approved. A new program description was issued in February 2006. In April 2006, individuals who were using the former CDCS service were given until April 1, 2006 to adjust their service plans to meet their new budget. Ineligible individuals were automatically eligible for the array of services available under the DD Waiver.

The program as described in 2006 was summarized in the brochures developed by the DHS:

You are eligible for Consumer Directed Community Supports if you:

- *Qualify for a program such as Elderly Waiver (EW), Alterative Care (AC), Community Alternatives for Disabled Individuals(CADI), Community Alternative Care(CAC), Traumatic Brain Injury Waiver (TBI), Mental Retardation/Related Conditions (MR/RC) Waiver, Minnesota Senior Health Options (MSHO) or Minnesota Disability Health Options(MnDHO)*
  and do not live in a hospital, nursing home, foster care home or assisted living, or
- *Are age 60 years and older and need services such as family caregiver counseling, respite, personal care, meals, rides, home modifications, homemaker or chore services or*
- *Have a cash benefit under a Long Term Care Insurance policy or have personal money.*

What services are available?

Considering your assigned maximum budget allowance from one of the above programs, you decide. Under Consumer Directed Community Supports you may be able to buy the kind *of help that fits your personal health or cultural needs. Most programs offer you help from a list of services provided by workers you don't know and who help you according to their schedule. If you want helpers you know, want to tell them what to do and when to come to your home and want responsibility making these arrangements, Consumer Directed Community Supports may be for you. Under Consumer Directed Community Supports you hire people you know such as friends, neighbors, or family members (e.g., spouse, grandchild, brother or sister, adult child, etc.) to help you. You have more responsibility under Consumer Directed Community Supports, but you may be more satisfied and comfortable with the help that you have picked yourself. You, or your representative, must be able to hire, train, and manage your workers. Consumer Directed Community Supports lets you decide how money for your services is spent.*

How does it work?

- *You decide how to spend your assigned budget allowance that is based upon your personal needs.*
- *You can hire people that you know such as family, friends, and neighbors to help you with your personal needs.*
- *You take on as much responsibility as you want to hire, train, and manage your workers.*
- *Someone can help you write a plan for how you want to spend your allowance, get it approved, and hire and set-up your workers.*
- *A fiscal management service will help you pay workers and purchases, withhold employment taxes, and keep track of your spending.*