

Forging A Partnership:

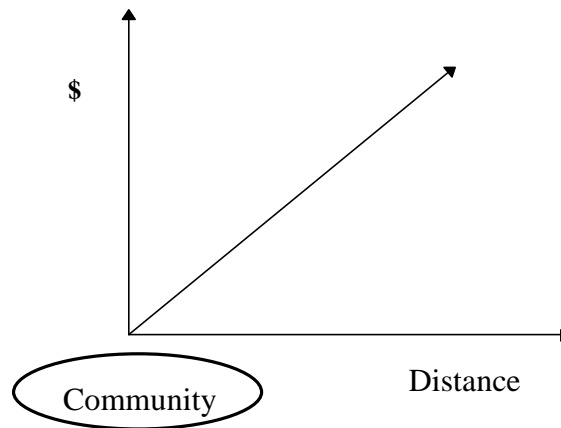
**Individualizing Funding and
Increasing Choices for People with
Developmental Disabilities
in Dane County, Wisconsin**

October, 1998

INTRODUCTION

It is the intent of Dane County to support all adults and children with developmental disabilities within the fabric of our rich and varied communities. We believe we are most likely to achieve that goal by providing the necessary support to enable each person we serve to make their own choices. They and those who speak for and with them will determine how to obtain services they need within the funds we are able to make available to them. Paying for support in this manner will forge a partnership with the people we serve, and build upon the strengths and connections of each person with their families, neighbors and fellow citizens.

In general, the greater the distance a person is from the social fabric of our communities, the greater the dependence upon public funding. The less involved the person being served is with the funding spent on their behalf, the less ability and incentive they have to maintain and build upon the support naturally available to them. This distance increases costs in both financial terms and in terms of the overall strength and diversity of our communities. Our current waiting lists are in large part a function of our historical underreliance on the knowledge, capacity and desire of the people we serve and their families. People ought to be able to obtain support in a manner which keeps them connected to their communities, and promotes just and equitable funding for all those in need of it.



Wisconsin continues to examine reforming its long term care system. Perhaps the key organizing principle of that reform, and one which has widespread agreement among all groups concerned, is the intent to integrate current community, institutional and Medicaid long term care funding into a single long term care benefit. Dane County intends to use that unified funding principle to change the nature of the economic transaction and allow each person we serve to act as a partner with us in determining how to use the funding allocated on their behalf. By so doing, we believe we will create a more flexible system which will promote choice and strengthen community within anticipated revenues.

Over time, we are changing the organizing principal for how money “flows” within our system to include a process in which each individual has the option of creating a plan to obtain the support they require within an individual budget based upon their needs. This process:

- establishes an individual rate for each person in need of support;
- provides each person with the knowledge and support needed to make informed choices;
- provides an effective system of accountability for paying for support;
- provides an effective system to help people obtain the outcomes they want in their lives; and
- maintains an effective county and provider infrastructure.

Since sharing the first draft of this plan in February of this year, we have received substantial input from the people we serve, their families, providers of services, and the Dane County Long Term Care Committee. This draft incorporates input from these sources, as well as from the original recommendations of the following individuals who worked diligently to bring together the various points of view reflected in *Forging a Partnership*. Substantial assistance has been provided to us through the Self-Determination initiative of the Robert Wood Johnson Foundation.

Art Taggart	Epilepsy Center	Ann Miller	Provider Agency	Dan Rossiter	Dane Co Staff
Betty Garvey	Parent	Camila Rucinski	Provider Agency	Deb Utech	State BDDS
Cathy Knight	WI Council on DD	Chris Sarbacker	Provider Agency	Diane Cobb	Dane Co Staff
Connie Wilkinson	Parent	Dedra Hafner	Provider Agency	Donna Winnick	Dane Co Staff
Fil Clissa	Dane Co ARC	Jack Taft	Provider Agency	Fran Genter	Dane Co Staff
Fran Bicknell	Autism Society of Wis	Janet Estervig	Provider Agency	Maya Fairchild	Dane Co Staff
Gary Jackson	Brain Injury Assoc of WI	Kim Turner	Provider Agency	Nan Cline	Dane Co Staff
Joanne Davis	Parent	Olwen Blake	Provider Agency	Roy Froeming	State BDDS
Judy Story	Parent	Shelley Rashke	Provider Agency	Sue Werner	Dane Co Staff
Maria Ritacca	Parent	Terri Johnson	Provider Agency	Wendy Stockstad	Dane Co Staff
Terri Winnas	Parent	Thomas Cook	Provider Agency	Dennis Harkins	Project Facilitator

Various other individuals, too numerous to mention, have also contributed extensively in helping create the changes needed to individualize funding, support and services. We particularly wish to thank those individuals receiving services and their families and friends who have agreed to be part of the initial learning and have shared their thoughts and lives with us.

How does this approach change Wisconsin’s and Dane County’s systems?

Wisconsin’s and Dane County’s current developmental disabilities services systems are heavily “slot” dependent, offering a menu of predetermined choices through contracts between service providers and either the county or state government. The cost of the slots or units of service may or may not correspond to the needs of each person. In simple terms we are increasing the role of each person to decide how to best spend the funding which is allocated on his or her behalf by federal, state or county government. A person* may purchase services through particular agencies, or may develop other more personalized approaches to obtain the support they need to live a life as typical and varied as members of our communities who do not require paid support as a result of a disability.

What specific outcomes do we expect to achieve?

Within their book *Reinventing Government*, Gaebler and Osborne suggested “The single best way to make public service providers respond to the needs of their customers is to put resources in the customer’s hands and let them choose.” We believe this fundamental change in how we organize and pay for support will have several significant outcomes:

- People will become the authors of their own lives and have the opportunity to personalize the support they need, rather than fit into the service models we have created for them;
- People will maintain, strengthen and create relationships in addition to, or in some cases instead of, paid services;

* We recognize that some people have guardians who play a significant role in helping make important decisions, including those discussed in this paper.

- At the very least we will spend no more money than we would otherwise expend on services;
- To some extent in the near term, and to a great extent over time, we may be able to reallocate funding to people on waiting lists by making better use of available funding;
- We will reinforce to families of younger children our intent to be partners in supporting their choice of what they need to care for their child with a disability within their family;
- We will reinforce to those currently satisfied with the community services they are receiving our intent to remain partners in supporting how they now and in the future obtain the support they need;
- We will reinforce to those currently living in institutions our intent to be partners in supporting them to obtain what they need to be able to live a richer life within our communities; and,
- We will give a clear and consistent message to all members of our Dane County communities of the value we hold in the capacity of all people, including people with significant disabilities, to be part of the natural web of relationships which is at the heart of our individual and collective quality of life.

The transition to participant-directed support and services

For the past two years the Dane County Department of Human Services has engaged in a careful planning and learning effort aimed at strengthening the public system of services and supports for children and adults with developmental disabilities, while building upon the current and potential strengths of our communities. Extensive exploration and planning in 1996 led to implementing two interactive learning strategies in 1997. These strategies combined working with a small group of individuals and families to choose how to obtain support and services with an individualized budget, while at the same time deepening our exploration of the issues identified by those individuals through an active and diverse working advisory committee. This process has been aided and informed by Dane County's involvement in the Robert Wood Johnson Foundation Self-Determination initiative with its more than 100 different sites across 29 states.

We believe the learning which has occurred to date suggests the outcomes we described above are achievable. We also believe those outcomes will be achieved only if we work carefully with people currently receiving services, those individuals waiting for services, and with individuals and organizations providing services as we make this transition. Since the widespread sharing and discussion of the original version of this planning document in February, work has continued on the important issues and concerns which had previously and have subsequently been identified. This document reflects the work to date on those issues and highlights both current and future learning activities which will inform the gradual transition to a system which increases the voice of the people we support in determining how to create the lives they want for themselves.

Our primary focus to date has been upon those parts of our system which primarily support adults. This plan also addresses services and supports to children and their families. Although we will not focus more deliberately on most services to children and families until 1999, there may be opportunities yet this year to work on aspects of increasing participant-direction for families, particularly in relation to changes which we hope will occur within the Community Integration Program.

THE STRUCTURE TO SUPPORT INDIVIDUALIZED FUNDING

We would like these changes in our system to be as elegantly simple as the organizing principle behind them. Because we are reforming an extremely complex and inequitable system of federal, state and county funding, the simplicity we desire has been somewhat elusive to date. We believe, however, the structure described below will allow us to individualize funding for all adults who enter our system or receive additional needed support beginning in October, 1998; and effective January, 1999, to offer the option to individualize how to receive services and support to all people currently receiving services.

Establishing an individual rate for each person

Each person receiving support from the system will have an Individual Rate based upon his or her need for support within a calendar year. People currently receiving services will have an individualized rate based upon actual spending for their services in 1998, with adjustments based on any increases provided in the 1999 budget. For people entering the system, the Individual Rate is based on the current reality in Dane County where typically two individuals with disabilities are supported together. Thus, the Individual Rate is the cost of support the County would expect to spend on a given individual living or working with another person with disabilities. It will be comprised of following four components:

- The 24 Hour Support Component

This component will establish the direct support (face to face) need for an individual and will account for hours that the person can function independently. This will be calculated for a 24 hour period and will include the associated cost that providers typically assign to each support hour. The number of hours of face to face support will be divided by two, assuming two individuals are supported together.

- The Support Broker Component

For people who use individualized funding to determine how they wish to receive support the overall planning, coordination and quality assurance roles of case managers will be assumed by support brokers. Consequently, the support broker component will be based on current use of case management time for individuals who require a given level of base support. Currently, the average case management time allocation is 3 hours per month. However, the range of hours vary from 1 hour per month to more than 20 hours per month. It is anticipated that the time allocation for support brokers will be similar to that of case managers.

Support brokers are required to have monthly contact with the individuals they serve, as well as semi-annual and annual meetings with the individual and others who provide support (or anyone requested by the person to be involved in such gatherings). As these contacts will be required, they will be paid for separately, outside of the Individual Rate.

- Housing Component

This component will use available information (the Madison Area Apartment Association) for typical rental units and will be calculated by geographic location. For individuals requiring live-in support, typical costs for 3 bedroom apartments (one bedroom per consumer and one for a companion or staff) will be used.

- Personal Living Funds Component

Dane County will use the Federal/State Bureau of Labor Statistics Expenditure Data guidelines for a household of two to establish the Individual Rate for Personal Living Funds which would include utilities, food, clothing, transportation, and discretionary funds.

Individuals will have the option of retaining their cash benefits (that is, continue to receive their own benefit checks) or direct others to become the representative payee. If individuals choose to retain their benefit checks, a supplemental amount beyond their benefit will be paid if deemed necessary.

To each of the components, certain adjustments will be made to account for individual need and circumstances. This would include need for atypical residential or vocational supports, unusually high co-payments, or unusually high housing costs (add-on's); or significant personal income or support by paid through Medical Assistance (subtraction's).

Once the four components are determined (with the necessary add-on's or subtraction's), the Individual Rate is derived. This Individual Rate will be converted to an Individual Rate Range by adding and subtracting 10% to the Individual Rate. For example, an Individual Rate of \$20,000 per year would be converted to a range of \$18,000 to \$22,000. This should account for minor discrepancies experienced in the Individual Rate calculations and will allow individuals to go above the Individual Rate for exceptional situations without any review.

Individuals will be encouraged to develop personal support plans which are less than the top of the rate-range available to pay for their support. Funding which is not initially obligated within a personal support plan will remain in reserve for that person's use, if necessary, later in the calendar year. Aggregated unexpended funding across all individuals will be available to serve additional people in subsequent years. It is anticipated that this additional funding could significantly reduce the numbers of people currently waiting for service and could ultimately change our system from crisis response to a meaningful, thoughtful transition process.

There will be an informal review and formal appeal process if the individual rate-range is thought to be inaccurate.

Providing information and support to each person: The role of the support broker

Our current system assigns a case manager to most individuals receiving services. Some individuals with extraordinary needs and some individuals entering the service system for the first time have county case managers. Most adults now receive case management from an agency which provides residential or vocational support to them.

In a system of individualized funding, support and services, primary case managers will evolve into support brokers, working on behalf of each person they support. As individuals enter the adult system, they will choose a support broker who will be independent of an agency providing direct services. Individuals currently receiving services who wish to utilize their individualized funding to obtain support and services other than through existing county contracts with their service providers would also choose a support broker independent of an agency providing direct services.

Support brokers will work with the individual or family to develop a support and services plan; to create a budget within the individual rate set by the county; and will offer coordination of support and services. They will have particular responsibilities regarding issues of health and safety, as discussed in more detail below within the section on effective outcomes. They will actively work to help people obtain support in the manner in which they want their needs to be met, within the limits of the funding available through the individual rate.

Support brokers must have knowledge and experience similar to that of case managers, but will understand their role as working for the person receiving support and services, rather than for the county or for a service provider. A learning process is being developed to enable potential support brokers, including current case managers as well as people who have not traditionally provided case management, to become more effective brokers in working on behalf of each person. Support brokers must be approved by the county, and will be required to participate in initial and ongoing training.

The required training will ensure that support brokers know and understand county and state policies on the use of funding. It will provide support brokers opportunities to learn a variety of ways to help people develop individual support plans. It will ensure familiarity with the differences among currently available supports and services and with other ways to help people get what they want and need. It will have a particular emphasis on the role of the support broker in helping prevent neglect or abuse, identify potential issues of health or safety if they arise, and act swiftly and effectively in response to any such concerns.

A person may choose a support broker, or if they do not have a preference, will be connected to a support brokerage agency. People will be free to change support brokers.

Developing personal support and services plans

Within the Individual Rate provided, each individual will develop an annual support and services plan, which will include:

- how the person wants to live (where; with what type and amount of support; doing and learning what they choose during the day, evenings, week-ends);
- those elements of a person's life which are "non-negotiable;"
- how support will be provided (both paid and unpaid);
- a budget describing what goods, support and services will be purchased;
- the "outcomes" a person expects from people and agencies providing paid support;
- identification of and response to health care needs; and
- identification of existing and potential issues of risk.

The plan will be developed with the assistance of a support broker chosen by the person, and with the support and assistance of others who are chosen by the person and their family (if a minor) or guardian (if an adult who has a guardian). The degree of formality/informality used to develop a plan will not be prescribed.

A basic level of support brokerage will be provided as a voucher outside of a person's individual budget. This will include the time required of a support broker to get to know the individual, assist the individual in developing a support plan, and provide at least monthly contact with and support to the person. Additional time and expense of a support broker may be purchased within the personal support plan, should the person desire to do so. Certain other expenditures will be available outside of the individual budget, including a minimal amount of getting started costs for persons who return to our communities from institutions; and mental health or behavioral consultation services and other support or services which have a "public service" component. As an example, it is anticipated that Dane County will continue to directly contract for the City of Madison specialized transportation.

Some expenditures are prohibited by county or Medicaid policy, such as the use of large Community Based Residential Facilities (group homes) and, obviously, illegal goods or services. The written plan will be submitted from the support brokerage agency to the county to authorize funding.

An effective system for paying for support

Perhaps reform of Wisconsin's long term care system will ultimately simplify the incredibly complex, sometimes baffling systems of payment and accountability for multiple funding sources. However, even if reform of long term care occurs, we must also respond to the regulations and idiosyncrasies of the Social Security Administration, federal and state departments of labor, and the federal and state tax systems. Dane County has attempted to be both flexible and efficient in paying for supports and services within these existing systems. It is clear, however, from our initial participant-directed support and services experiment, that we need to streamline our payment and overall funding accountability systems in order to reduce cost; to allow money to flow quickly to those who have provided goods, services or support; and to assure that people who provide personal support receive the benefits to which they are entitled.

We believe the most cost-efficient way to manage the flow of money will be through the creation of *Fiscal Management Agencies*. These agencies will be responsible for paying the bills to service providers, for contracting with generic providers (such as professional employment agencies or *fiscal intermediaries* which will act as the employer of record to handle taxes, worker's compensation, and other benefits for individuals who provide support to a participant outside of a provider agency) or for making payments to any other business or entity included in the plan.

An effective system to help people obtain the outcomes they want in their lives

We are aware that people with developmental disabilities, particularly individuals who have difficulty speaking for themselves, have been subject to abuse and neglect within institutions, within community settings, and within their own homes. We are dedicated to helping people be as safe as possible within an imperfect world. In addition to bringing the full weight of the laws of this land to bear upon individuals who neglect or abuse others, we have created a multi-faceted approach to assure that people living in our communities are safe and secure.

We are equally committed to helping people live a life of their choosing with others who love and care about them. The components described below will focus on increasing the capacity of everyone who works with the people we support to listen to their voices, to respect their knowledge, to accept their gifts, and to share their journeys. These interlocking elements of program and civic integrity include:

- Assuring that all persons involved in providing support are adequately trained and are familiar with the individual support plan, with particular attention to non-negotiables and the identified issues of health and safety;
- Continuing to have clear procedures for immediate referral to and response by the Dane County Department of Human Services on issues of potential abuse or neglect;
- The active role of a support broker in helping identify "non-negotiable" outcomes and issues of health and safety for each person and in assuring those outcomes and issues are addressed on an ongoing basis;

- The active role of support brokers in affirming they have current personal knowledge of each person's living situation and that either a) they can affirm that the person is living in safe and decent conditions, that the person's money is appropriately managed, that the person is receiving needed health and dental care, and that the person is receiving adequate assistance to deal with the consequences and vulnerabilities of her or his particular disability; or b) if one or more of these conditions is not met that they are personally involved in efforts to assure that they are met.
- Creating a Quality Assurance Board to review, analyze and provide feedback on identified problems with services on an individual and collective basis;
- Ongoing review of the implementation of a sample of support and service plans by members of the Quality Assurance Board, with regular feedback to support brokers, service providers and to the Department of Human Services on how to strengthen any supports or services which do not appear to be responding to the outcomes people desire, as well as accumulating information to help others within our system learn from exemplary supports and services which are identified through this process;
- Developing a report card format within a regularly updated resource guide, as a source of information about provider excellence;
- Strengthening the voice of self-advocacy within Dane County, so that people with developmental disabilities are better heard by others in our communities;
- Mentoring to people with disabilities and families by other people with disabilities and families who have had experience in directing their services and support;
- Satisfaction surveys and focus groups;
- Periodic review of systemwide performance on both health and safety and on quality of life issues by state staff;
- Continued involvement with the Adult Protective Services Unit at Dane County;
- Continued liaisons with the various local police/sheriff departments;
- Revising the State/County Grievance procedure to include the potential for an informal mediation role by the Quality Assurance Board;
- Working to assist each person to have people in their life who care about them in addition to service provider staff;
- During 1999 an added component of the annual review for each adult will be to describe the most important individuals who are currently involved with the person, both those in paid and unpaid relationships. This information will be important to help us collectively address the issue of how to provide a stronger voice for people whose disabilities may limit their effectiveness in making important decisions. Other ways we will begin to better address this issue include:

- a requirement that the individual’s support broker meet with the person and any agencies supporting the person at least every 6 months (in addition to the minimally required monthly contact between the support broker and the person), unless the person requests that such meetings not occur;
- a decision by a support broker can be brought to the attention of the county in one of two ways if a member of the team believes the decision does not represent the desire or intent of the person receiving support:
 - through the county grievance process if the decision relates to contracted services, or
 - through mediation offered by the county Quality Assurance Board; and
- review by the county of significant changes in a person’s plan if a concern is raised that the changes raise issues of safety or potential misuse of funding.

Assuring continuity of services

Many people currently receiving services are satisfied with their current service providers and are content with the amount of personal involvement they now have in arranging for services. People who wish to continue to receive support from the agencies now providing support to them will be able to easily do so. In such circumstances, the only significant change from our current system will be sharing information with the person on the cost of services they are receiving and on the option available to use the individual budget differently should they choose to do so.

Helping providers through the transition

Dane County currently has a wealth of agencies dedicated to helping people create their own homes and engage in work and other activities away from their homes. Representatives of provider agencies have been actively involved in the planning which has occurred over the past two years. They have been supportive of the effort to develop a means of paying for support that allows each individual to create her or his own life through a personal support plan and an individual budget. They have also played an important role in raising the many questions which start with, “How will we ...?”

A transition plan must respect the history and integrity of the current agencies, both for the sake of the agency and the sake of the individuals they serve. Dane County will continue to have a contract with each provider agency for the purposes of continuing support for persons who choose to continue to receive services through county-provider contracts, as well as to ensure uniformity in administrative practices and procedures, to support agency wide initiatives, and to provide the capacity to continue to respond to unique issues which may arise during the year for a particular agency.

The Dane County Department of Human Services will continue to work collectively and individually with all providers on issues which arise. We hope the greater freedom that people we serve will have to choose how to allocate their individual budgets will allow agencies even greater opportunities for innovation, creativity and excellence in how they provide support. County staff have met extensively with provider agency administrators, staff and board members in developing and modifying this plan, and will continue to do so.

Addressing the needs of people with high costs for services

We have typically found that the higher the cost to support an individual, the fewer choices and less freedom the individual has. While this is particularly true for people in the State Centers who have, on average, the most expensive service plans, it is also true for individuals living in the community who have high costs currently associated with their support.

The DCDHS Adult Services Division will pay particular attention to people with the highest costs associated with their services, in hopes of offering assistance which will both increase a person's freedom, and decrease overall costs. This focus will include transforming the current county case management function with people living at the State Centers and other ICF-MR facilities into more of a support broker role, helping people identify how participant-directed support and services would allow them to create a better life within our communities. As people leave the Centers and other ICF-MR facilities, they will identify an independent support broker to help them develop and implement an individual support and services plan.

If people now living in the community who have exceptionally high service costs wish to make the transition to more individualized support, staff from the Adult Services Division will offer support to them and to their support broker to explore ways to maintain or improve their quality of life, while also learning from and with the person receiving support whether the cost of services and support can be reduced over time.

Services to children and their families

For children and families receiving support, the DCDHS system is an excellent example of how public funding can augment family and community resources. It is a highly effective family-centered system, and in some important ways is family-directed as well. Could a more family-directed approach conceivably result in an even more effective and responsive system?

In contrast to the approach we are taking for adults, it does not appear that learning with a few families and gradually adding people to a pilot in an ongoing cycle of action-learning-reflection-action would be feasible for children's services with the possible exception noted below. Relatively few agencies are involved in providing support to children and families, and at this point in time they would have great difficulty responding to one new family at a time. We are thus recommending an alternative approach, which is to bring a group of people together in 1999 to focus specifically on how we might maintain and improve outcomes for children and families who receive support, and improve access to the system for those who are currently waiting.

A relatively small number of children are, however, currently receiving services through the Community Integration Program (CIP). In response to the efforts of Dane and several other counties, the Wisconsin Department of Health and Family Services has obtained approval from the federal Health Care Financing Administration to dramatically increase the flexibility and opportunities of CIP funding for people who use individualized funding to create or obtain the support and services they need. Once the Wisconsin DHFS determines how this new opportunity will be implemented, we will explore extending it to children who receive CIP funding in Dane County.

Role of the County

While particular roles of county administration and staff are changing, the overall commitment to and responsibility for people with developmental disabilities who need support will not. The Dane County Department of Human Services will play an active role in support to and oversight of service providers and support brokers. The Department retains its responsibility to as best as possible enable Dane County

citizens with developmental disabilities to feel safe and secure as they live their lives as fully as possible within our communities.

Specific ongoing roles for the Dane County Department of Human Services include:

- **System Planning and Coordination:** DCDSHS will maintain contracts with service provider agencies, individual support brokers who support more than a single individual, and support brokerage agencies in order to assure basic levels of performance and sharing of information; to maintain an awareness of all aspects of systems performance; to identify and respond to identified service gaps or opportunities for improvements in support and services; and to communicate with county, state and federal government regarding both fiscal and human service needs and outcomes.
- **Helping People Enter and Understand the System:** DCDHS will facilitate easy access to the system and transition through the system, including determining eligibility for support and services, initial assessment of support needs, individual rate setting, and providing initial and ongoing information about accessing support brokers and service providers.
- **Systems management and payment for support and services needed outside of the individual rate:** DCDHS will continue to administer funding to individuals and providers for services or support which fall outside of the person's individual budget.
- **Case Management Unit:** DCDHS will maintain a case management unit to assist individuals in transition or crisis, similar to the role the county plays within the current system. The unit will also provide person specific consultation for individuals in unique or particularly challenging circumstances.
- **Safety & Protection:** DCDHS will continue and expand its role in assuring safety and protection of individuals who receive support and services.
- **Quality Assurance/Program Integrity:** DCDHS will coordinate the expanded number and variety of ways in which people with developmental disabilities and those who care about them will be able to evaluate and understand the quality of services and support being provided.
- **Crisis response:** DCDHS will maintain its capacity to assist individuals who experience a crisis in their lives.

NEXT STEPS

We believe the transition towards increasing the voice of those who receive support from our system is best achieved gradually, in the following manner:

- Through the remainder of 1998 and thereafter, all adults who first enter the community system from waiting lists, from graduation from high school, or from institutions will receive an individual budget and assistance to use that budget to determine how they wish to receive support.

- Effective January, 1999, all adults currently in services will have the option to continue to receive services through county contracts with their service providers or to exercise increased choice in obtaining support and services within their individual rate. Each person will receive information about their individual budget and the choices available to them. Individuals may
 - choose that the county continue to contract for services directly with providers, or
 - choose to select a support broker outside of an existing provider agency and begin the transition to creating a new plan with more involvement and greater flexibility in how to use their budget to obtain the support and services they need.

Between now and the end of 1998, the following actions will have been completed or structures established to foster increased choice and the potential for greater self-determination by the individuals we serve within our system:

- individual rates determined for all adults currently receiving services;
- written information on increasing individual choices available for people receiving services and their families, as well as ongoing forums for discussion;
- many and various opportunities for people to learn how to use their individualized funding to obtain support and services;
- a list of available support brokers, and guidelines for who may serve as a support broker;
- initial and ongoing support broker training;
- initial and ongoing training of self-advocates in understanding the options available to them;
- training opportunities for those who are exercising more choice over how they receive support and services to become “mentors” for others who wish to do so;
- opportunities for families who are exercising more choice over how they receive support and services to become mentors for others who wish to do so;
- one or more agencies to process payments to providers and to pay other bills ;
- one or more support broker agencies;
- one or more agencies to process payroll and to provide employee leasing services to people who wish to select their own staff;
- a program integrity structure which continues current quality and safety assurances, and adds a Quality Assurance Board and a Quality Improvement process;
- support available to particular agencies to begin a more systematic process of offering increased choice to all or a portion of the people they serve;
- a process for continual learning with and from those who are involved in managing their own budget for support and services;
- appointment of a Choices Council to advise the county on ongoing implementation of these increased opportunities for people within our system.

The learning which is continuing to occur will be actively shared with county administration, county board committees, the public and the Choices Council. The Choices Council will consist primarily of people receiving support and services and family members, and will include provider and voluntary agency representatives. The Choices Council will make ongoing recommendations to the county regarding further implementation and learning in strengthening the collaboration among people with developmental disabilities, families, agencies and citizens as we increasingly individualize funding and opportunities for the people we serve.

APPENDIX: Services to Children and their Families

To a great extent, Dane County's system of support for children with disabilities and their families already incorporates the vision and reality of the type of partnership we are attempting to forge among adults with developmental disabilities and the various elements in the system which supports them. There are, however, significant differences between the manner in which individualized funding is evolving to support adults, and the current system for children and families. There are also important differences among four primary programs supporting children and families: Birth to Three, Family Support, Extended Day Care and related programs, and Foster Care.

Birth to Three Program

Birth to Three is an entitlement program which enables children and families to receive the services which families and the agency agree are needed to benefit the child who has a disability. The program was designed to be centered around the child's needs, as identified by families. Families have extensive input into identifying those needs, requesting particular supports and services to meet them, and choosing from available people and vendors to respond to them. The program is governed by very specific rules.

The entitlement nature of this program, the high degree of federal and state regulation of it, and the significantly broader eligibility criteria than for other services would seem to limit our capacity to make this program even more individualized than it already is or to integrate its funding with other sources of funding for children with developmental disabilities.

Family Support Program

The Family Support Program is administered in Dane County through the Family Support and Resource Center (FSRC). In addition to simply (or not so simply) administering the Family Support Program, FSRC also manages COP funding for children and maintains the waiting list for Family Support and/or county case management (or the "low intensity service" list, since FRSC attempts to provide at least some type of contact and support to children and families who are waiting for more intensive FSP, COP, or CIP funding).

Family Support Case Managers work with families using an approach entirely consistent with individualized funding. Within the limits of funding available to the family, Family Support staff ask the family to identify what they need, help them identify how to meet those needs through their own or other community resources, and generally support their decision in how to use available funding to pay for other needed support. The program operates on the basis of attempting to provide support based upon what people say they need.

Family Support Case Managers actively engage families in the decision-making process, and typically respect family decision about how to spend available funding. They help families act as collective stewards of scarce public financing. Families are aware that funding is limited. To the extent they request paid support beyond their need, funding is reduced for others who are waiting. FSRC is clear about the importance of maintaining and expanding community connections for each family.

Despite the consistency in core values and approaches between the Family Support Program and the individualized funding we have created for, there are significant differences in operational details. FSRC has not developed a functional assessment and related rate-setting process. "Individual budgets"

are thus negotiated on a relatively subjective basis, with an important subjective factor being the energy and informal resources of a family, and their perception of how much the child's disability affects their family. While in many regards this fluidity contributes to the success of the program, it can result in families which choose not to expend energy or natural support receiving more funding than families with greater needs. There is no guarantee that families will choose to act in a way to better utilize community resources and make a conscious decision to "ration" public funding potentially available to them in order to support more people.

A key role within the system we are developing for adults is played by a support broker who can be paid by the person receiving support through the person's individual budget in addition to a separate amount of funding outside of the person's individual rate. Within the Family Support Program, the support coordination is provided in a flexible manner by Family Support Case Managers and is entirely reimbursed *outside* of the funding available to each child or family. This flexible support coordination is perceived by FSRC and by families as a critical component in providing the support which has made this program so effective. It is not "accounted for" or included within the individual budget which the family directs; thus, there are no incentives for a family to limit the use of this service.

The Family Support Program operates on an annual budget, which tends to set the boundary around how many families it has the administrative and staff capacity to support. At this point in time, individuals who came to FSRC with an Individual Budget would likely be met with the response, "We're sorry, but we do not have the staff to help you spend that money to get what you need." The idea of providing a fixed individual budget to each family raises at least four questions in this regard:

1. Is there an alternative to going to FSRC for family support?
2. Is the Family Support Program capable of responding to "one new person at a time?" Since much of what they provide is staff dependent, can they expand their staff capacity to provide support through receiving small, additional increments of funding in an unpredictable manner?
3. Can the Family Support Program "depackage" or otherwise "price" the support they provide to respond to what individual families might request from them if each family was negotiating from their own Individual Budget?
4. Can Case Manager costs be added to the individual budget available to each family? If so, would families make different spending decisions?

Extended Day Care/Respite Care

While these programs provide critical support to many individuals and their families, they are a type of service or support which Dane County now purchases on behalf of families through an annual contract. In a system in which each individual would decide how to spend available funding, these programs would be challenged to figure out how to set rates for their management and coordination role, and how to expand support for "one person at a time." For example, the Respite Care Program allows families to determine how much respite care they will use, where the respite care will occur and to select their respite care workers. However, recruitment, screening, training, and follow-up support to respite workers are general staff functions which cannot be easily predicted or allocated to an individual family. Since Respite Program staff are currently "at capacity," it is difficult to figure out how it could expand to meet the needs of one or a few families even if additional funding were available to particular individuals.

Foster Care/Institutional Care

Dane County is strongly committed to supporting children to grow up within families. Foster care and institutional care are not choices among an array of supports and services, but rather a last resort response to complex issues of support and interaction among a child, a family, and our communities. Children in foster care or institutional care and their families receive staff support through county Case Managers within the DCDHS developmental disabilities services unit. Case managers at both DCDHS and FSRC now support children and families in which there may be a risk of out-of-home placement.