Nearly 150 years ago John Stuart Mill, in “On Liberty,” made the simple observation that “liberty consists of doing what one desires.” In a nation founded on the promise of securing “the blessing of liberty” for all, people with disabilities have found themselves often forced to exchange their personal freedoms for the services and support they need. Unwilling to accept that the need for support is incompatible with personal freedom, growing legions of individuals with disabilities, their families, advocates, public officials, and service providers have developed and promoted new ways of increasing the control that people with disabilities have over their own lives and futures.

This issue of Impact focuses on various aspects of and experiences with supporting personal freedom through self-directed supports and individually managed budgets. It includes articles from policy, service, and individual/family perspectives illustrating what is possible when self-determination guides service provision. While control over one’s own services and supports and the resources that finance them does not directly and unequivocally yield liberty, in these pages readers will find evidence of the enormous contributions that such approaches to human services can make to lives of greater independence and personal satisfaction.

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My Life and Consumer-Directed Community Supports

by Nathan Perry

It’s a clear, cool evening and I am riding my bike with John (he’s in charge of my support team and also helps me with things like being more healthy and understanding my spirituality). It is my first bike ride in quite awhile. At one point he says to me “Wow! Nathan, I can hardly keep up with you.” Because the bike trail is close to where I live, I know the area better than he does…so I am leading the way. Even though I haven’t gone riding lately, I think I am doing pretty well and I know that John does a lot of biking. Once or twice we slowed down because we wanted to enjoy the animals behind the fence surrounding the wildlife refuge next to our bike trail. We were lucky; we got to see several deer, lots of geese, and a red fox. By the time we were done biking, both of us were tired and had sore muscles; we had gone about 13 miles in an hour and 15 minutes. Later, I bragged about it to my brother Brad. I’m glad we went biking that night; it was great.

This is just one small story about what makes consumer-directed community supports (CDCS) such a great support for me in my life. For me it means mostly being more independent and doing the things I want to do and not always the things others think or say I should be doing. But, that’s not the way things always have been. I just

Perry, continued on page 26]
The self-determination movement is bringing about perhaps the most radical change in a generation in the way we think about people with developmental disabilities and the formal system vested with meeting their needs.

In 2002, a group of individuals who had been endeavoring to implement self-determination in their states and localities got together in Manchester, New Hampshire to share their experiences and to distill the lessons that they had learned. To frame the issues, the group began with a consensus statement regarding the “non-negotiables” of self-determination in practice. Their formulation provides a straightforward set of principles (Robert Wood Johnson Self-Determination Program Office, 2001):

- People decide what they want.
- There is support to people to make decisions.
- There are real options from which to choose.
- The process is simple and person-centered.
- With control comes responsibility.
- It is an approach – not a model, not a program.

One important and rapidly growing feature of administrative support for self-determination is providing persons with developmental disabilities and/or families with individual budgets that they control for the purchase of services and supports within established guidelines and with assistance as needed. The impact of this and other specific shifts in the service system on important outcomes for individuals is still somewhat difficult to determine given limited empirical information. However, data from the National Core Indicators (NCI) does suggest that immediate changes are taking place. The NCI is a collaborative performance monitoring system supported by the National Association of State Directors of Developmental Disabilities Services and the Human Services Research Institute. It assesses service and support outcomes for individuals with developmental disabilities and families in 20 participating states. Those individuals in the most recent round of data collection who were identified as having individual budgets (4212 out of 8065) were more likely to live independently; make choices about where they lived, with whom, and where; dictate their own schedules; take advantage of community activities; and know their case manager and to report that they received help from their case managers in securing services (HSRI, 2004).

To provide a platform for the exploration of how to embed self-determination principles into state developmental disabilities systems, the Robert Wood Johnson Foundation (RWJ) funded a 19-state demonstration initiative. A parallel evaluation of the effort was also funded. As part of the assessment of the systemic effects of self-determination conducted by the Human Services Research Institute, the following outcomes were identified (Bradley et al., 2001):

- **Changes in rate structures.** Significant changes have taken place in the way that services are funded – both during the RWJ demonstrations and subsequently. These changes include the development of individual budget methodologies in many states, the creation of individual service agreements, portability of budgets from provider to provider, and a shift to prospective rates based on cost ranges rather than retrospective of fee-for-service payments.

- **Changes in the role of case managers.** The evaluation of the RWJ demonstrations strongly suggested that the workload for case managers/service brokers in the initial stages of developing a consumer-directed set of supports was heavier than for traditional residential clients. The work involved in designing the supports, assisting the individual and/or his or her family to make decisions among options, the mobilization of supports, and the development of an individual budget was highly labor intensive.

- **Changes in quality assurance.** The emergence of self-determination has posed challenges to traditional quality assurance systems that are built on the assumption that individuals live in residential settings with continual staff support. Persons with individual budgets are more likely to be living by themselves, with their families or with one other individual and to be operating with sporadic rather than constant supports, and with
It is clear that the philosophy of self-determination has and will have a profound effect on the way services and supports are funded.

need to be able to rely on information systems that are highly flexible and that allow for individual oversight as well as rapid shifts in allocation levels based on changes in individual circumstances.

- Changes in the mission and focus of self-advocacy organizations. The emergence of the self-determination movement has galvanized self-advocates and has provided them with a rallying cry.

- Changes in the management of provider organizations. Though not a universal change, many providers have begun to retool their organizations and to retrain their staff in order to recognize the unique capabilities of the people they support, and to support individuals to make decisions that guide the course of their lives.

The final test of any significant social movement is the extent to which it seeps into public policy. That threshold was crossed when the Bush administration launched its New Freedom Initiative, which included new programs, rules, and funding opportunities that stressed individualized funding, choice, and movement from institutional settings. The recent solicitation for the U.S. Centers for Medicare and Medicaid Services' Real Choices grants listed the following as one of the key principles on which funds will be awarded: "Exercise meaningful choices about their living environments, the providers of services they receive, the types of supports they use and the manner by which services are provided" (U.S. Department of Health and Human Services, 2003, p. 4).

It is clear that the philosophy of self-determination has and will have a profound effect on the way that services and supports are funded. Whether or not this effect becomes a permanent and positive influence on our field depends on three things. First, it depends upon the extent to which states are successful in molding Medicaid Home and Community-Based Services waiver funds to be put to the service of self-directed supports. Second, it is tied to the extent to which there is investment in training of direct support professionals and case managers so that they become facilitators of self-direction. And thirdly, lasting change depends on the extent to which states and other administrative entities establish and maintain the flexibility that is crucial to the successful implementation of self-determination in the range of settings across and within states.

References


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Resources on Supporting Self-Determination

- www.selfdeterminationohsu.org. This Web site of the Center on Self-Determination at Oregon Health Sciences University contains information and resources that promote the self-determination of people with disabilities and ongoing health conditions. Information categories are leadership, education, employment, community, and health.

- Shifting Power and Control. This book provides a variety of activities to teach direct support providers, administrators, service coordinators, families and individuals about self-determination. It was developed at Monadnock (NH) Developmental Services, the U.S.'s pioneer agency in self-directed supports and budgets. Available from MDS at 603/353-1304 or at http://www.mds-nh.org.

- This is Freedom: Self-Determination Across America (video, 25 minutes). A documentary that presents the first in-depth look at interviews conducted in 1998 with self-advocates, family members, and others from across the country speaking openly about the struggle for self-determination. Hopes for the future as well as frustrations with the present service delivery system are discussed. Available from the Institute on Disability, University of New Hampshire, 603/862-4320 or http://iod.unh.edu.

- Impact: Feature Issue on Support Coordination and Self-Determination. This issue of Impact addresses the evolving roles of service coordination and support brokering in assisting people to define and realize life goals. Available from the Institute on Community Integration at 612/624-4512 or http://ici.umn.edu/products.
Recent initiatives in state developmental disabilities systems are demonstrating the positive outcomes that can occur when people with disabilities control the supports they receive. While significant progress is being made, the shift to self-directed systems requires a broad-based commitment and bureaucratic flexibility that is frequently difficult to achieve. In contrast to past initiatives, self-direction does not involve a straightforward transition from one type of service model to another. Self-direction is not a type of service, but an approach to configuring the way supports are made available to the people who need them that requires changes in the fundamental building blocks of the system itself.

**A Framework for Empowerment**

The ability of the individuals receiving support to direct and manage the services they receive rests on the power they have to influence decisions related to funding, staff selection and supervision, individual program planning, and outcome assessment. In self-directed services, people are empowered through individual budgets that give them decision-making authority over the expenditure of the funding that is allocated to pay for the services identified in their individual plans of care. The individual budget can increase a person’s access to the services they need by enabling them to purchase supports that are not available through the traditional systems of service delivery.

State policies regarding the development and implementation of individual budgets differ from one jurisdiction to another. Each approach, however, must:

- Identify a person’s needs.
- Select services that best address the needs.
- Determine the amount of service or support necessary to adequately address each need identified.
- Determine a cost or an amount to reimburse the providers of the service.
- Integrate the services together into a set individual budget amount.
- Establish policies and procedures for filing claims and receiving reimbursement.

The process of individual budget development may appear straightforward. Each step, however, reflects a number of interlocking policies and procedures that must function in concert to achieve outcomes that are fair, accurate, valid, practical, and above all, understandable by people receiving support and their families. Self-directed services in general, and individual budgets in particular, offer opportunities for individual control and decision making that are not available from traditionally structured programs.

People with disabilities and their families are interested in gaining increased control through self-direction and individual budgeting, but many are frustrated by the complexity of the process and express concern that they do not have the information they need to make informed choices regarding participation. Individuals considering the move to self-directed supports want to know how the process functions across their state and throughout the country, and what they should look for in deciding whether or not this approach is right for them. This article describes the key features of state individual budgeting procedures and identifies issues that should be considered by individuals and families as they begin directing their own individual budgets.

**Informing Choice**

In response to increasing requests for information and technical assistance on individual budgeting practices nationwide, the National Association of State Directors of Developmental Disabilities Services (NASDDDS) recently surveyed state officials on the nature and extent of the practice in their respective states (Moseley, Gettings and Cooper, 2003). Eighty-four percent of the states responded to the survey. The key findings of this study, described below, identify the extent to which individual budgets are in use nationally, and highlight key aspects of the individual budget development process that people with disabilities and their families need to understand in order to become informed individual budget “consumers”:

- **Individual Budget Availability.** Individual budgeting options were available to people receiving publicly funded specialized DD services and supports in 75% of responding states. The extent of the availability...
of individual budgeting alternatives varied considerably, with the majority of states indicating that a basic individual budgeting process was in place, but it was limited by geographical area, funding mechanism, or program type. Eligibility to receive an individual budget was influenced by the nature of the funding received and the type of program in which the person was enrolled. States, counties, and provider organizations need to help people receiving support and their families understand how the individual budgeting process works and the factors that influence availability and eligibility in their area.

- **Assessing the Need for Support.**
  State individual budgeting strategies generally employ one of three approaches to assessing an individual’s needs. The first method can be described as a “developmental” approach that identifies and evaluates the needs to be supported through the person-centered planning process, relying upon the members of the individual’s program planning team or “circle of support” to select the essential objectives to be achieved. The second “statistical” approach uses a standardized needs assessment protocol to identify needs and in some cases, set allocations. The third method combines elements of the other two approaches to inform decisions of the circle of support and individual program planning team. It is important that individuals receiving support and their families understand the process through which the individual budget is developed and implemented. State agencies and provider organizations need to communicate to individuals with disabilities and their families the basis upon which their needs are identified and evaluated for funding.

- **Determining an Allocation Amount.** The majority of states determine the services and supports an individual is to receive and the amount of the individual budget during the person-centered planning process. Almost 70% of the states responding to the survey reported that individual budgets were derived through a “developmental” process based on discussions of the person’s needs for support and assistance. Approximately 30% of the states responding to the survey separated the process of determining individual funding allocations from decisions regarding how a person’s funds are to be deployed. These states typically use statistical processes based upon standardized tools, such as the *Inventory for Client and Agency Planning* (ICAP), the *Developmental Disabilities Profile* (DDP) or another state-specific instrument to determine the individual funding allocation or target budget. In the individual budgeting process, states determine the rates they will reimburse service providers in several ways, including:
  - Statistical means that set rates of reimbursement through the application of statistical methodologies that weigh a number of cost and service related variables in the development of specific or all-inclusive payment amounts.
  - Pre-set cost or service ranges established by the state and enforced through regulation, waiver program policy and procedures, negotiation with provider entities or any of a number of other means.
  - The establishment of rates and service amounts based on a determination of the actual costs the provider is expected to incur based upon past performance or expenditure history.

  Self-directed systems of support must be flexible in order to encompass the wide range of different activities offered by both traditional and nontraditional services. The funds identified in the individual budget should not be tied to agencies or particular providers of service, but rather to the individual. Funds need to be portable and able to “follow the person.” States need to communicate to individuals and families receiving support the process by which the overall budget amount is determined in their state. In addition, states need to help them understand the method used to determine the amount of funding that will be made available to purchase each of the individual’s services identified in the person-centered plan.

- **Spending Limits and Responding to Changes in Support Needs.**
  Almost 75% of state respondents reported that the process of individual budget development results in the establishment of a set amount of public dollars (a spending limit) that is made available to finance services for a particular eligible recipient. While the budgeting process may identify a spending limit or set amount to cover the cost of services, the funding level must be able to be changed based on the needs and services identified in the person’s “plan of care.” The individual budget cannot “lock-in” a person to a fixed rate that is unable to be adjusted in accordance with changes in support needs. Individuals who are self-directing can be expected to experience changes in their support needs over time for a number of legitimate reasons related to their particular home, job, and social environment. Some changes in service need are minor or temporary and have a minimal impact on the person’s budget or plan of care. Others, in contrast, may require the planning team to reconvene to construct a new service plan and budget. In either case, the process of individual budgeting must be able to adapt to changes quickly and not present a barrier to the identification and implementation of new necessary supports. States need to educate individuals receiving support and their families about how to recognize that additional or different services are necessary and how to request a change in budget amount if the needs are no
Adults with developmental disabilities want control over their lives. They also want to live in the community, work, have friends, be healthy, and stay safe. They want to live life just like any other citizen. Expectations like these are fueling a steady shift in service systems. Community systems are increasingly offering services that promote integration and self-direction. These approaches also provide greater opportunity for service recipients to have extensive control over managing their own services.

To succeed, however, adults with developmental disabilities often require support. As a result, families are increasingly taking an empowered role in managing services with and on behalf of their adult family members with disabilities. To effectively carry out this role, families should keep three pointers in mind: a) always start with person-centered planning and an individualized budget, b) dare to be creative about the supports your family member needs, and c) don’t confuse the value of controlling one’s life with controlling operational details.

Start with Person-Centered Planning and an Individualized Budget

Always start with person-centered planning and an individualized budget. Person-centered planning is a process that is directed by the individual (and perhaps family and support network members as well) to assess his or her strengths, preferences, capacities, and needs, and to specify the supports that must be offered to address those needs. An individualized budget that the person controls gives a boost to the process. This budget sets the amount of funding that is available to the individual to meet the specified needs.

Individual budgets are compiled in a variety of ways. Some states use systematic assessment to arrive at a data-based allocation. Others use means that invite open discussion and negotiation. Some combine the two methods. Even where discussion and negotiation are used, however, there is a limit to what any individual may ask for, given the need to assure that the overall budget is used efficiently to be able to respond to all individuals needing assistance. Each approach carries its own strengths and shortcomings. Regardless of the approach used, it is important that participants are treated equitably and that, ultimately, the process is fair to all.

Another issue related to budgets pertains to whether individuals should be told of their budget allocation before they engage in their planning process. Some say that if individuals know how much they’ve been allocated, they will needlessly spend to the cap. Others counter that withholding such information undercuts the planning process and subtracts power from the individuals to manage their own services. You may have no control over how individual budgets are figured, and you may or may not be told what the allocation is. If you aren’t told, ask. Participate in a person-centered planning process with as much information about the amount allocated as possible. The more you know, the smarter you can be about tailoring services to a specified budget.

Dare to Be Creative About Supports

Dare to be creative about the supports you or your family member needs. A system that encourages self-determination must be flexible enough to accommodate a variety of life choices. The days of channeling individuals into a limited array of preset service options are over. Yet, “control” over a budget does not mean that you can use public money to purchase any support you want. Aside from needing to stay within an allocated budget, state agencies will want assurance that the supports purchased will address the needs specified in the person-centered plan. Agencies may also impose restrictions on services judged to be unsafe, untested or ineffective. And, of course, if the services are being purchased through Medicaid— as most are today— state officials will insist that the services sought are “Medicaid reimbursable” and that a proper audit trail can be provided.

Before settling on a plan of supports, make sure you understand what supports are permissible and which are not. Understand what you or your family member wants. Be creative! Then, do your best to craft a supports plan that delivers what is needed and is acceptable to the funder.

Don’t Confuse Controlling One’s Life with Controlling Operational Details

Don’t confuse the value of “controlling one’s life” with “controlling operational details. Given careful planning and an individualized budget, the goal is for individuals to receive the supports they need to live the lives they want. Managing one’s own services, however, can come with added responsibilities such as tracking expenses; hiring, firing and paying workers; adhering to legal requirements; and maintaining needed paperwork. Do not
confuse control over these operational details with self-determination.

In most instances, participants are offered administrative support to offset these management burdens. “Brokers” are often charged with developing person-centered plans, securing supports, and monitoring quality. “Fiscal intermediaries” handle much of the associated paperwork. Use these supports whenever you can. If they are not made available, insist that they become available. Families should not have to pay for the authority to manage services with time spent on administrative details.

Support the Individual’s Wishes

For many families, managing services tied to a budget allocation is not a new idea. Family support programs for children have always embraced family empowerment themes and offered families great latitude in deciding what services were needed and how they were delivered. Systems that promote self-determination build on this experience, extending the idea of personal control over services to adults with developmental disabilities and, because of the nature and impact of disability, to their families. As self-determination practices evolve, however, a gritty question has emerged: “Who is the ‘self’ in self-determination?” Often, when we ask this question, the quick response is “the person with disabilities.” Our conversations with self-advocates, however, make us wonder. We find that family members often take on a chief decision-making role, sometimes diminishing the role that individuals might play in controlling their own lives.

We understand that this can be a complex and touchy issue related to the age of the individual, the person’s intellectual disability, the culture of the individual family, and the nature of the decisions that must be reached. Still, people with developmental disabilities urge their family members to think hard about how decisions are reached over services. And so, there is a fourth pointer for families: Self-determination is ultimately about supporting the individual to live the life she or he wants, not the life that family members want him or her to live. Given this counsel, we look forward to the strong partnerships that will certainly emerge, within the context of self-determination, between adults with developmental disabilities and their families. After all, we understand that self-determined individuals come from knowledgeable, empowered families.

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Choices and Connections Via the Web — www.LifePages.org

Consumer-directed supports, consumer-controlled housing, and other individually-oriented innovations offer people much greater control of their lives. Many participants have noted that while they are generally pleased with such options and the freedom they provide, they wish they had more options for shaping one particular area of life: creating meaningful and enjoyable social and recreational activities outside the home, and building relationships in the community. Partners in Community Supports (PICS), a joint venture of six non-profit service providers in the Minneapolis/St. Paul area, is using the Web to address this need.

LifePages.org (www.lifepages.org) is an interactive Web site designed to increase opportunities, choice, and support for community inclusion for people with disabilities. It connects users with information, with one another, and with the community at-large. This Web site was developed through a partnership of PICS and the University of Minnesota’s Research and Training Center on Community Living, with support from the Administration on Developmental Disabilities. The site has been created, piloted, and evaluated in the Minneapolis/St. Paul metropolitan area, and is now expanding coverage to communities outside Minnesota.

LifePages.org features sections titled Recreation/Leisure, Services, Community, and Resources that connect people to a range of information, from respite providers, to music events, specialized equipment and clothing suppliers, volunteer opportunities, and faith communities. Users can search for activities and resources by keywords, date, or any number of other variables. Users can also receive personalized information by creating a personal interest profile that allows them to indicate the type of information they’re most interested in, and receive e-mail alerts when matching events, activities, or resources are added to the site. In addition, the site has an “invitation” feature that connects individuals who are interested in the same types of events; this feature is limited to use by people supported through PICS or its partner agencies, and access is controlled to reduce risks for vulnerable users.

LifePages.org has averaged 3,800 visitors per month during its first nine months, and it continues to evolve in response to needs and desires of users. Through partnering with organizations in other locales the scope of resources and opportunities it offers will continue to expand, providing yet another option for supporting individuals with disabilities and their families to shape their lives.

Contributed by Anne Roehl, LifePages Project Coordinator, and John Gehan, Associate Director, PICS, Minneapolis. For more information or to inquire about bringing www.LifePages.org to your area, contact Anne at annroe@PICSweb.org or 952/854-6364, ext. 107.
Finding, Keeping, and Training Staff When Individuals and Families Control the Budget

by Amy Hewitt

One of the greatest challenges in supporting people with developmental disabilities today is finding, keeping, and training people to provide direct support. While this challenge has become increasingly difficult due to an increased demand for services and changes in the demographic make-up of our society, it has been evident since the inception of community human services for people with developmental disabilities. It often results in poorer outcomes and poorer quality of services than individuals and their families should expect (Hewitt, Larson & Lakin, 2000; Larson, Hewitt & Lakin, in press). There is no doubt that to improve quality of services and services to people with disabilities we must find solutions to the challenges of high turnover, increased vacancy rates, poor training, and inadequate compensation for people who work in direct support roles. Opportunities to do so may exist in the flexibility afforded to individuals and their families who control their own budgets and services.

Current Direct Support Workforce Challenges

One of the greatest challenges faced by provider organizations, individuals, and families is finding a sufficient number of reliable employees who will show up on time and when scheduled to provide direct supports. Many states have conducted studies of vacancy rates in direct support positions and these studies have found that vacancy rates for direct support professional (DSP) positions range from 6% to 17% (Larson, Hewitt, & Knobloch, in press). This means that on any given day about 1 out of every 10 positions in direct support is unfilled. The end result is that individuals and families likely either receive fewer services because there are not staff to cover the hours or they receive services from staff who are working many hours of overtime. In a recent evaluation of Home and Community-Based Services in Minnesota, it was found that only 46% of families reported they received the total number of hours of respite services they were allocated, and 56% said in-home supports were not available when needed (Hewitt et al., 2000).

A second challenge is low wages and inadequate benefits. It is well-documented that people in direct support roles earn low wages and have access to limited employee benefits. While a national study conducted since 1990 (Braddock & Mitchell, 1992) several states have conducted independent wage and compensation studies. These studies (conducted between 1998 and 2002) were recently summarized across 42 states. They indicated that the average starting wage of DSPs in non-state community residential settings was $7.33 per hour and the average wage for all DSPs was $8.68 per hour. These community wage rates compare to much higher rates of pay in institutional and public facilities in which DSPs work and have an average starting wage of $9.49 and overall average wage of $11.67 (Polister, Lakin & Prouty, 2002). The availability of affordable health benefits to DSPs is also an increasingly important problem, especially given the rising costs of health insurance. Most employers do offer health care benefits but only to a portion of their employees and not necessarily at an affordable rate. Typically, employees who work full-time have the option of health benefits to which they contribute, but those working part-time are usually not afforded this option. Addressing problems associated with low wages and inadequate benefits is critical to resolving the workforce challenges. Currently, many DSPs earn less than the poverty rate for a family of four and cannot support their families unless they work more than one job (Larson et al., in press) and many raise families without access to health care. As a result many DSPs work stressed and burned out, tired and overworked – which puts them at much greater risk of maltreatment (College of Direct Support, 2003). Resolving wage and benefits issues is not only critical because of the effects they have on DSPs personally, but also because wages have consistently been shown to be the number one predictor of higher turnover rates, which negatively affect the lives of people who receive support services.

A third challenge is turnover rates (annual crude separation rates), which have consistently been shown to average between 45% and 70% since the beginning of community support services in the 1970s (Larson, Hewitt & Knobloch, in press; Braddock & Mitchell, 1992; Lakin, Bruininks, Hill & Hauber, 1982; George & Baumeister, 1981). One of the greatest challenges is ensuring an accurate picture of national turnover rates across various service types. A national study has not been conducted since 1990 and those state and local studies that have occurred often do not gather turnover data using the same calculations and definitions. But, the bottom line is turnover is high, and that results in challenges for families and individuals. Imagine if you depended upon staff for medication administration or personal care, or for support so that you could go to work, meet other family obligations, be involved in your community. Further imagine that each year more than half of your employees left their positions. This would likely feel stressful and frustrating and it often results in bad things happening such as people with disabilities being left alone, parents having to quit jobs to care for their family member or people not getting the ser-

vices they were determined to need. A fourth challenge is staff training. The service system for persons with developmental disabilities has long had inadequate, minimal training requirements for DSPs. Service provider agencies often report that they do not have adequate money to support sufficient training of DSPs. DSPs also report that their training does not meet their needs, is inadequate to prepare them for their jobs as DSPs and/or is boring.

**Solutions to high turnover, increased vacancy rates, poor training, and inadequate compensation of DSPs may exist in the flexibility afforded individuals and families who control their own budgets and services.**

(Hewitt, 1998). Other challenges related to training include the difficulty in freeing staff from doing direct support to attend training and the lack of availability of training at times that are accessible to DSPs who work multiple jobs and varied shifts. While training is regulated in almost every state, the mandated minimal training barely prepares DSPs to keep people safe. The required skills of DSPs far exceed those provided in typical mandated training (Taylor, Bradley & Warren, 1996). While we struggle to get DSPs basic training, we need to provide far more training that is competency-based and offered prior to being given the substantial responsibilities of direct support. Without adequate training that focuses on the needs of the people being supported there is increased risk for people being harmed and maltreated.

**The Direct Support Workforce and Individually-Controlled Budgets**

The use of individually-controlled budgets and the related flexible support and service options available to individuals and families is a relatively new concept. It has been provided to only a small percentage of citizens with developmental and intellectual disabilities. There are indications from early evaluation studies in Michigan, Minnesota, New Jersey, and Oregon that direct support workforce issues such as wage, turnover, and recruitment difficulties can often be lessened by individuals who control their own budgets. Two states have reported that one of their main motivations for initiating individually-controlled budgets and self-management of services was in response to the workforce crises they were facing (Hennepin County, 2003; Walker, 1999).

Many individuals and families report that when they have control over who they hire and fire they are able to find higher quality personnel and use particularly committed people such as friends and family for support providers (Head & Conroy, in press; Walker, 1999). Studies also indicate that DSPs are often paid higher wages when they work for people who individually control their budgets (Hennepin County, 2003; Head & Conroy, in press; Walker, 1999). Additionally some families have reported they are able to actually get the services they have been authorized because they can find staff even when agencies say they cannot, and that they receive more hours of support than under agency-directed supports (Walker 1999).

There are numerous other benefits of receiving supports when individuals and/or families control their own budgets. Studies have indicated that people have more self-determination and control over many aspects of their lives beyond just staffing issues. For example, people can choose what they want to do more often and go the places they want to go more frequently. The implications for DSPs are that they have to have the skills needed to support people to make their own choices and to take risks.

**Interventions and Solutions for Individuals, Families, Organizations**

Irrespective of the type of services and supports people with developmental disabilities receive, it is critical that they have well-informed and stable direct support employees. If they are to be effective in controlling their own budgets and managing their own personnel, they need to use effective interventions to increase the probability that employees will be stable and effective employees (not unlike effective service agencies).

Because individuals and families who direct their own budgets have more flexibility, many have reported that they are able to pay higher hourly wages and have the flexibility to use fewer hours in order to pay higher wages. The removal of administrative fees and the “middle man” makes this possible. In addition to maximizing the wage of DSPs, it is important to ensure that when needed, DSPs have access to health insurance benefits. Purchasing these options through the fiscal intermediary/employer of record agency can make the benefits more affordable to the employee. Other benefits DSPs may receive are paid time-off for sickness, childcare issues, and vacation. It is important to plan for and include these costs into the person’s individually-controlled budget. Many individuals also add educational benefits as a part of the employee’s benefit package – paying for college education or other training opportunities. Other benefits can also include more creative options such as the use of bonuses. Some families have developed an outcome bonus system whereby employees are assigned specific outcomes that they support the individual to achieve; if the outcome is achieved, they receive a bonus on their annual gross earnings. Other individuals and families have created room and board situations for students so that by working to support an individual with a developmental disability for 10-20 hours per week they get free room and board. Families should be encouraged to think creatively about how to use their resources to shape individualized wage and benefit packages to

[Hewitt, continued on page 28]
Self-Directed Support Corporations: What a Difference They Can Make

by Jackie Golden

Self-directed Support Corporations (SDSCs) are, simply, a small legal support provider for one person with a disability. But they are also much more than that. The SDSC puts control and direction of supports back in the hands of the person with a disability needing the supports. The SDSC follows an incorporation process and develops a not-for-profit agency. The SDSC is overseen by a board of directors consisting of trusted allies of the person with the disability. The board must get their direction from the person with the disability. The person with the disability may select to be the President of the board, a voting board member or not serve on the board at all – it is the person’s decision. The board of directors must find ways to listen to the person, even if the person doesn’t have a formal communication approach. It is for this reason that the board of directors must consist of people who believe in the person needing supports, and that the board have a vision that embraces and respects the person’s desires and support needs. A person with the disability then has a support network of people who believe in him or her. It is self-directed because the board, which receives its direction from the person, decides what supports are needed and how supports are used. These supports are custom-designed around the person’s wants, dreams, and needs.

How Does a SDSC Work?

Each state in the United States has procedures and regulations for becoming long-term care providers. The SDSCs follow those same procedures and regulations. The only difference is that the SDSC only designs supports for one person, rather than hundreds. Like other providers the SDSC has to follow the state guidelines, regulations, inspections (if required), as well as federal guidelines. In this way, the SDSC is accountable for public dollars spent and also accountable to the person who is being served with those public dollars.

There have been questions around the SDSC concept. One question is “Does the state have to do something different within their regulations or waivers to allow the SDSC to form?” The answer is simply, no. If your state has long-term care providers, then they can also have SDSCs. They are the same as any other provider that follows the same set of regulations. Some states have “waived” some requirements for the SDSC, because these requirements didn’t make sense for a provider agency of one. The SDSC must provide quality services, maintain a fiscally responsive system, and assure accountability at every level to the state and federal governments.

The SDSC approach is quickly gaining popularity across the United States as this approach offers many things to a person needing supports. The best thing is more control and freedom in their own life. People who care about them, not people who don’t even know them, assist in the arrangement of personal supports; we all know that we are better off when we have people who care about us in our lives. In addition, this approach provides accountability to the state and federal governments, creating a win-win situation for a person with a disability, their trusted allies (friends and family), and the government.

So, you may ask, “Is the SDSC model for everyone?” The answer to this question is also no. This concept should be viewed as another option. The problem with our systems has always been that we approach supports as a “one size fits all” model. Over the years we have discovered that this model doesn’t take into account the individuality of each person and also it is a costly mistake. So the SDSC may not be for everyone, but for many who have ventured down this path, the changes it has made in people’s lives are remarkable.

In 2001, the Administration on Developmental Disabilities awarded Inclusion Research Institute (IRI) a grant to promote the SDSC model throughout the United States (see www.selfdetermined.org). IRI has been tracking the establishment of the SDSCs approach over the past two years. Currently there are approximately 55 SDSCs across the United States and the numbers are growing rapidly. States that have these small boards already established are Maryland, Colorado, Oregon, Missouri, Utah, Oklahoma, Virginia, Pennsylvania, Arizona, and Tennessee. One illustration of what an SDSC can do can be found in the example of the SDSC established for my own son Joshua.

Joshua’s House Incorporated!

Joshua’s House Incorporated (JHI) is much more than a name of a corporation. It is my son’s – Joshua Golden’s – lifeline. JHI is a SDSC that was designed to deliver the supports Joshua needs to live successfully and fully included into his community. Simply put, JHI is a provider agency, but doesn’t provide services to 500 people – it provides custom designed supports for only one person, Joshua Golden.
Joyful Care, Inc.: Tennessee’s First Microboard

by Del Ray and Madeline Nichols

Joyful Care, Inc., Tennessee’s first operating microboard which began operating May 26, 2002, was set up to provide services for our daughter, Joy Elizabeth (Joy Beth) Nichols who suffered severe brain damage at the age of nine years from herpetic encephalitis. The brain damage hampered normal physical development of her left side. The herpes virus reactivated in January 2002, destroying the retina in her left eye.

Joy Beth requires 24-hour care. She is non-verbal but vocal, feeds herself (her food is cut into bite-size pieces) but sometimes has to be coaxed to eat slower, and needs assistance in dressing and bathing. Her seizure activity continues to be a challenge. Changes in her medication brought about through working with the Epi Care Center in Memphis, along with use of the vagus nerve stimulator, a device that sends periodic signals through the electrodes to the brain by way of the left vagus nerve in the neck to reduce the frequency and duration of partial onset seizures (similar to cardiac pacemakers), have helped to decrease the length of the seizure. Still, she averages 75-100 seizures a month. The seizure activity continues to weaken her left side; currently she is wearing a left leg brace to stabilize her ankle and to stop the knee from hyper-extending. She also has limited use of the left hand.

We, Joy Beth’s parents, have strong family values, believing that the family who know and love her best should have the responsibility of caring for her needs. The microboard concept has made this a reality. The Medicaid waiver funds come to the non-profit provider agency that her family and friends have formed: Joyful Care, Inc. The most obvious benefit for us in creating this microboard is that we select and hire the staff to care for Joy Beth. Three of the original four employees hired by Joyful Care, Inc. in March 2002 are still working for Joy Beth. The former residential agency was experiencing a huge staff turnover causing major staffing problems for Joy Beth; the lack of competent, stable, experienced staff was a nightmare. Her behavioral issues occurring at the time were proven to be staff-induced by their lack of knowledge about how to effectively work with her. A benefit of the microboard is that we can train our staff with mandated state training emphasizing Joy Beth’s special needs. Since we developed the microboard, there have been no reportable behavioral incidents, compared to many the previous year with the larger provider agency. Joy Beth is happier, healthier, and more secure with this situation.

Since the microboard is operated by a volunteer board of directors we have minimum overhead, allowing better pay rates and benefits for staff. Joy Beth is currently receiving occupational therapy, physical therapy, speech, and nutrition services chosen by Joyful Care, Inc. Fortunately for us these are independent contractors who bill the state directly, reducing our paperwork and overhead expense. Joyful Care, Inc. also provides personal assistance Monday through Friday from 8am-2pm, allowing Joy Beth to be out in the community as her health permits. This has proven to be very beneficial to her. The same personal assistant has been working with her since January 2003. Acquiring these and other supports and services seems to happen more quickly when all our attention and emphasis is focused on one person’s – Joy Beth’s – needs and quality of life.

The microboard has been ideal in allowing Joy Beth’s siblings, their spouses, and children to take an active role in her care. The board of directors meets and the Circle of Support take place in the evenings at Joy Beth’s home so that those family and friends who are employed can attend.

We have learned several lessons along the way. One is that attending optional provider meetings and training sessions offered by the state makes filling out reports easier and keeps us up-to-date on any changes. And since we aren’t “business folks,” it’s been important to locate state and other resources to help us learn how to operate a small business and attend to things such as local, state, and federal regulations; taxes; payroll; and insurance. Another lesson is that we need to network with larger agencies for certain mandatory training (CPR, First Aid and Medication Training for Unlicensed Personnel). And a third lesson is that we have better results when we recruit staff through referrals from current staff, friends, and family rather than through paid advertising.

Overall, the microboard has been God’s provision for us. We better understand how “the system” works and doesn’t work. Joy Beth’s quality of life has dramatically improved. Her siblings and their families are allowed to be actively involved in all aspects of her life. Plus, we as parents can sleep at night knowing that the staff caring for her know her and love her.

Del Ray, Madeline, and Joy Beth Nichols live in Blountiville, Tennessee. They can be reached at 423/323-5367 or delmadn@aol.com. Pictured are Joy Beth with her parents (front row), as well as her siblings and their children and spouses.
Beyond Traditional: The Arc of North Carolina’s Employer of Record Service

by Lisa Poteat and Holly Hunnicutt

In August 2001, The Arc of North Carolina launched the first employer of record service in the state. Currently, 41 individuals or families in 14 counties are utilizing the services.

I want a provider that won’t leave me stranded. I want to know the people who are coming into my home to provide services for my child. I want someone who can be an extension of me, someone who will do the things I direct them to do when I cannot do them. I want more control. I want to hire my own staff and I want to pay them more so they’ll stay with me. These are the types of comments The Arc of North Carolina heard from individuals with disabilities and family members as we began developing methods of providing supports to people beyond the traditional approach. We first began providing direct supports and services for people with developmental disabilities and their families. We developed an advisory committee composed of people with developmental disabilities, family members, case managers, and administrators from our local developmental disabilities section and vocational rehabilitation office, and we began to listen carefully to people who expressed a desire for something beyond the traditional provider approach. The advisory committee assisted us in translating people’s needs and desires into new approaches that would work under North Carolina’s current system of rules and regulations.

Employer of Record Services

In August 2001, The Arc launched the first employer of record service in the state. This service provides a mechanism for people with disabilities and families to take more responsibility in hiring and managing their own support staff, while The Arc ensures that all the necessary rules and regulations are met. To begin the process, each person or family receives information about the total funds available to them to support the services they need. Through person/family-centered planning they ultimately determine which services will meet their specific needs within the framework of state defined service options. They begin building a personal budget by projecting dollars to be earned through the provision of those services, as well as the associated costs, such as paying employees and purchasing administrative services from The Arc. As they add up costs and make adjustments to their proposed budget they may have funds available to purchase “extra” supports and services outside what the system typically offers, such as private counseling. After services are rendered, billed for, and payment received by The Arc, bills for those “extra” supports and services can be handed to The Arc for payment. Functioning as a fiscal intermediary, The Arc pays the bill and subtracts the payment from the total of the individual/family’s funds. This provides some initial flexibility in using the funds available for support services to meet individuals’ or families’ needs and requests.

In addition, each person and/or family participating chooses the administrative services they want to receive from The Arc versus the administrative activities they will choose to perform themselves. For instance, they can pay The Arc for placing an employee recruitment advertisement in the local newspaper, or they can choose to do that activity themselves, or choose to recruit in a different way. As they make these choices they begin to manage their budget for their personal support funds. They choose from a “menu of administrative services,” defining how much they want to be involved in that process, or agreeing to pay The Arc to handle those activities for them. Each administrative item on the “menu” clearly shows The Arc’s cost so each person/family can make informed decisions from the start.

Individuals and families develop job descriptions based on their unique support needs, and develop pay scales based on their personal budget comprised of the funds available to pay for their sup-

ports. With assistance from The Arc’s staff they interview and hire their support staff, assist in training support staff, manage support staff on a daily basis, and manage the budget for their services. The Arc’s assistance in each of these areas is individualized, and based on what each person or family needs and wants. The Arc also provides a revenue/expense statement for each individual or family at the end of each month. Guiding this process is an agreement between the participant and The Arc. The contract outlines each party’s agreed-upon responsibilities, while taking into account the personnel requirements for The Arc as the legal employer of record. The contract is a flexible document which can be easily amended as an individual or family chooses to take on more or less responsibility in the process.

**Growing the Participant Fund and Self-Determination Fund**

As an individual or family grows in this process, they become comfortable doing more for themselves and they require and request less administrative services and assistance from The Arc. The more activities they perform for themselves the more money they have available in their budget to meet their needs. These “savings” are what some providers may refer to as “profits.” Each person’s or family’s “savings” is split at the end of each six-month period, with half remaining in The Arc’s self-determination development fund, and half reserved for each individual’s or family’s participant fund. At the end of each six-month period the participant fund may be available for use by the person or family for services or items they feel will improve their quality of life. Many individuals and families use their participant fund to purchase services or items that are either not available through the current system, or require long approval processes, or waiting periods or exorbitant spending with approved vendors. Examples of uses of such funds include:

- Purchasing durable medical equipment and repairs.
- Purchasing special cleaning products and food items for children with extreme allergies.
- Purchasing special air filters for homes to improve health conditions.
- Purchasing therapeutic services not funded by Medicaid.
- Purchasing eye glasses.
- Purchasing numerous common, sensible, and inexpensive products or services that are not available through our current system.

The Arc maintains its self-determination development fund to support the development and dissemination of the employer of record services, and hopes to be able to fund services to people who have no funding in the future.

**Service Goals and Outcomes**

Through its employer of record services, The Arc of North Carolina has created a way for people with disabilities and families to have a lot more control and ownership throughout the entire process. In addition, individuals and families can make better use of the dollars available for their services than with traditional provider approaches. These methods are based on the practices of listening, partnering, and sharing all information about earnings and expenditures with each individual or family involved in the process. Knowledge is power, and information about money translates to more control for the person who holds the information. The Arc’s goal in its employer of record service is to share the information and share the control of the dollars available to purchase the necessary supports for each person or family. Shared information and control are the most essential elements in this process.

Participants in the employer of record service tell us their lives have changed and are still changing. They express appreciation for this process and our partnership with them. They feel “freed up” to do more of what works for them in a system that often “ties down” the people it is designed to support. They also feel that they have more control throughout the process. More control means more responsibility, and our history shows that the learning curve is steep for most individuals and families in the beginning. Extra assistance from The Arc is available in the beginning and throughout the process as people build experience and confidence in their abilities and skills in hiring and managing their own staff and in managing the budget for their support services. This is a very rewarding and empowering process for participants, requiring dedication and hard work. As people improve their skills they decrease their costs for administrative assistance from The Arc. This results in a decrease in the funds they owe to The Arc from their individual budget, and consequently participants have more discretionary funds available to meet their various needs.

Currently, 41 individuals or families are utilizing The Arc’s employer of record services in 14 counties across North Carolina. Committed to making customer-controlled supports available to as many people as possible in the state, The Arc has begun collaborating with our local chapters across the state to work with individuals and families in their communities who desire more control over their services and supports. Through continued development and implementation of support brokerage and employer of record services, The Arc is committed to changing the face of direct services and supports in this state to one that is controlled by the people receiving those services.

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I would like to introduce myself to you first of all. I am Buren Harrelson and I have a disability. My disability is cerebral palsy (CP). I have been affected with CP since birth, unable to walk or physically do much for myself. Because of this, at an early age I knew that it was going to be important for me to focus on education. I was first educated in special education classroom settings and then I became mainstreamed into a regular public school classroom setting when I was eight years old, in 1978. I completed high school in 1989 and went on to community college in 1990, receiving my AA degree in general education in 1993. I then transferred to a small liberal arts college where I received my BA in business and economics in 1996. I have since gone on to hold several part-time jobs in my community. I also sit on several local boards dealing with developmental disabilities. I will not take time to list them all here, but a few of them are the Mayor’s Committee for People with Disabilities, First in Families of Southeastern North Carolina, and the local Home and Community-Based Waiver Approval Committee.

Now that you know a little about me, let me tell you about The Arc’s employer of record services and how I became involved. Our program is set up to be an alternative to traditional support systems, giving families and individuals with developmental disabilities more freedom to decide what types of supports they actually need and who will actually be offering those supports. I first became involved with the program in December of 2000 because I had been with several traditional providers in our community and that approach did not work for me because of the lack of freedom in choosing my support staff.

Since I have been involved in this new service I have faced a tremendous learning curve. For example, I have had to learn how to write a detailed job description, how to go through and read applications for employment, and how to actually conduct employee interviews, including learning what I can and cannot say or ask while conducting the interviews. One of the most important things that I have learned over time is that the individuals I interview may have preconceived notions about what I can and cannot do as far as my disability is concerned. It is very important, however, not to let the individual’s notions cloud the interview process in any way. I have found that the best way to handle this problem is to actually explain my individual limits. Another thing I have learned after conducting numerous interviews with different individuals is that no matter who I talk to, salary and other compensation always comes up and, depending on the individual situation, I may want to ask advice from a mentor. It is very important that I do not offer too much information regarding compensation during the first initial interview process because each employee’s rate of pay would be based on a number of factors, including qualifications, experience, and funds available in the individual budget to pay staff. With traditional provider agencies, talking about salary is not a problem because support staff are hired at a set rate, which is not left up to the individual receiving support. With The Arc’s employer of record service, individual families and persons with disabilities are given a choice on rates of pay based on individual budgets.

Traditionally, with community-based supports, individuals and/or their families are not given individual choice on how supports are directed, and are often matched up with inappropriate support persons due to either lack of training or different personalities that clash. With The Arc’s employer of record services, however, individuals are given much more control over what services and supports are needed and how these supports are to be directed. Individuals and families are free to choose their support staff, when the staff is scheduled to work, and most of the time how hours of support are to be utilized. Whereas, with traditional support services a supervisor known as a qualified developmental disabilities professional tells the families and/or individuals who they will work with and when those persons will and will not work. The supervisor will also tell the individual and/or family who they can visit out in the community.

I first became involved with The Arc’s employer of record service because I had been with several traditional providers in our community and that approach did not work for me because of the lack of freedom in choosing my support staff.

nity, where they can go, how long they can stay in one place, and who they may or may not talk to while they are out with a direct care support person in the community. When a person has situations that does not work, particularly because of conflicts in personalities, the individual and/or their families are most often told that they must work things out with the employee already providing support, or not receive services at all for given periods of time. Also with a traditional provider agency, there are times that situations arise in which individuals are sometimes put in danger or in which potentially dangerous situations may be overlooked. With The Arc’s employer of record services, if such situations do arise, the individual and/or family is given the option to replace the employees.

One big difference between the two types of programs is individuals and/or families using the traditional approach may have employees to work with that they have never seen before, who don’t know any of the routines or habits of the individuals, or their likes and dislikes. The individual may require support eight hours a day; however, with a traditional provider, he or she might have three different individuals providing that eight hours of support. With The Arc’s employer of record services, normally if a person receives eight hours of support at once, it’s provided by someone the individual has hired who is familiar with them, and their routines, likes, and dislikes. With this program, unlike traditional provider agencies, once an individual and/or family has hired someone to offer community support, that person is not taken away from the individual to offer support to another individual without permission.

The Arc’s employer of record approach works best because individuals and families receiving services are given enough credit as people to be able to do what works best for them and their lives and in each individual situation. This program works well most of the time. However, it is important to re-member that everything is not always going to run smoothly. The challenges faced in the employer of record services are very different than challenges faced with a traditional provider. Because of the increased levels of responsibility, the employer of record approach requires much more time and energy on the part of the individual receiving services. In the employer of record approach, just as with a job match, the individual must be a good fit in order for the service to work well.

In conclusion, the employer of record service works best because individual and/or family needs are looked after first instead of looking at a bottom line of a profit/loss statement as often seems the case with a traditional program. Opportunities such as the employer of record service should be made more widely available to individuals and families because individuals and families are the experts when it comes down to having their own needs met and how best to meet those needs.

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QualityMall.org: Offering Free Resources on Consumer-Directed Supports

QualityMall.org is a Web site offering individuals with disabilities, families, service providers, and others a wide range of free information about consumer-directed and other person-centered supports. Its primary purpose is to collect and share information from around the country and abroad that is related to or useful in promoting quality of life for persons with developmental disabilities. It is not a seller of products or services, but uses the metaphor of a shopping mall to help connect visitors to the best resources available.

In its 20 “stores” and 85 “departments” (meaning its broad and specific topic areas) it offers nearly 1000 different resources. For those interested in consumer-directed supports, the first stop should be the Person-Directed Services Store, where “departments” include Consumer-Directed Budgets and Supports (35 resources), Person-Centered Planning (48 resources), and Self-Determination (69 resources). In another area, the Self-Advocacy Store, are resources that support efforts to promote individual and group empowerment. In the Service Provider Store, there are resources that offer suggestions and provide checklists to help people select services and service providers that best fit their specific needs and expectations. And the Community Center has resources on friendship and inclusion, recreation and leisure, sexuality, and travel and vacation.

QualityMall.org was developed by the Research and Training Center on Community Living at the University of Minnesota’s Institute on Community Integration, the National Association of State Directors of Developmental Disabilities Services, and Human Services Research Institute (HSRI), with funding from the federal Administration on Developmental Disabilities. The “mall” is a metaphor with two meanings: the idea of a single place where you can find just about anything you are looking for, and a public gathering place that includes everyone. And that is what QualityMall.org is.
Community Involvement Programs (CIP) is a non-profit organization that has been providing services to individuals with disabilities since 1971. Founded as an outreach of Westminster Presbyterian Church in Minneapolis, Minnesota, the organization’s programs have always been innovative. For instance, its early apartment training program provided opportunities for adults with developmental disabilities to learn independent living skills while residing in an apartment building with other individuals supported by the agency. This congregate setting was eventually replaced with scattered apartments that the agency rented; participants were placed with roommates and regularly met their support staff at the administrative offices to work on individual goals or to attend a variety of classes on community living skills. Today the program supports 80 individuals who live in a variety of settings, including several participants who have purchased their own homes.

The evolution of the apartment training program exemplifies the commitment we have made to providing services and supports that are innovative and reflect current best practices. The mission of CIP is “As listeners, learners, and leaders, we will stand with and support people with disabilities in their communities as they pursue their personal dreams and goals.” The organizational leadership believes that best practices are based on what matters to the individual, and the only way to know what matters most is to listen and learn.

In January 2001, CIP was selected as one of a number of provider agencies to contract with Hennepin County to provide fiscal intermediary and employer of record services. In Minnesota, most families that have individually controlled budgets are participating in the Consumer-Directed Community Supports (CDCS) option of Minnesota’s Mental Retardation and Related Conditions Waiver (MR/RC Waiver). The CDCS option allows individuals and families to develop a plan based on the person’s unique needs and situation. Each person is given an annual budget based on criteria determined by the county. Once approved by the county, families are then responsible for implementation of the personal support plan. Most choose to use an agency to provide fiscal agent and employment services.

The decision to seek involvement with CDCS was based on our belief that self-determination will continue to be a driving force in the direction of services to individuals with disabilities. We believe that supporting individuals and their families to implement an individualized support plan is an obvious way to further our mission. The administrative infrastructure existed that made it feasible to take on the additional administrative tasks with a minimal strain on existing resources. As the program grew, staff were added to support the increased number of families to whom we provide service.

As a fiscal intermediary, CIP pays for services provided and bills the state Medical Assistance program for reimbursement. For example, an adult receiving CDCS services might attend a weekend respite program that provides opportunities for outdoor recreation. The agency sponsoring the respite program submits an invoice to the fiscal intermediary agency for payment. The fiscal agent then submits regular billing to the state to be reimbursed. Any approved expenses listed in the Community Support Plan will be reimbursed.

As an employer of record, CIP hires people selected by the family or individual to provide support to the person receiving CDCS services. We ensure that all requirements for employment are met, including submitting a criminal background check form to the state Department of Human Services. The family is responsible for recruiting, hiring, and training their employees; we provide brief orientation materials for all employees that cover topics required by law or regulation. However, the materials clearly state that the family is the best source of information on how supports should be provided and the expectations of each staff person. We provide families with a packet of employment forms for each employee, as well as time sheets for their employees to submit. The managing party (often a parent, sometimes the service recipient) is required to sign all time sheets to verify that the hours were actually worked.

Although the employee is directly supervised by the family, we have made efforts to include CDCS employees in the activities of the organization. They are invited to an annual employee recognition event and are eligible to apply for a tuition reimbursement through CIP’s Employee Educational Assistance Program. We are currently participating in the College of Direct Support, an Internet-based nationally-available college for direct support professionals offering coursework in critical skill areas such as individual rights and choices, documentation, and safety at home and

in the community, as well as important issues such as community inclusion and making friends. Participation in the college is offered to all interested families.

The fee structure for CIP’s fiscal intermediary and employer of records services is based on a monthly administrative fee plus a percentage of wages to cover payroll taxes and insurance. The monthly fee of $135 covers all administrative costs of providing both types of services. In addition, the MR/RC waiver is billed 11% on all wages paid to cover payroll taxes and insurance. Families have expressed their appreciation for the simplicity of the fee structure, which makes it easier to plan and budget for a year’s expenses. The fees cover the salaries and benefits for two full-time employees as well as a half-time director.

With rare exceptions, families have been overwhelmingly positive about their participation in the CDCS program. More than one family has told us, “This has changed our life.” For example, one family has two children who receive services. Due to a variety of issues related to the disabilities of their children, the family has never been able to take a vacation. The CDCS option allowed the family to have their support staff accompany the family on a vacation “up North” – a Minnesota tradition for thousands of families, but never before possible for this one. The staff were paid for providing supervision to the children so that the whole family could participate in the many activities at the lake resort. The waiver did not pay for the vacation itself – families are still responsible for lifestyle choices such as vacations and travel; however, under the CDCS option the waiver will pay to remove the barriers to participation that are related to the individual’s disability.

Some other examples of how families have used the CDCS option include:

- A number of people have used funds to pay for a personal trainer at a local health club or YMCA. By paying for a personal trainer, individuals have made better use of their membership; instead of just going to the Y, the person who receives services has the opportunity to learn specific skills that contribute to life-long health and fitness.
- Several individuals have used CDCS funds to participate in creative arts programs as an alternative to attending an adult day habilitation program. Acting classes and music lessons have provided an excellent opportunity to increase self-esteem, enhance a variety of communication and physical skills, and provide a valued creative outlet.
- A number of families whose children experience challenging behaviors have used resources for karate lessons. Instruction for young people in the traditional martial arts had reportedly helped some of their family members by teaching self-discipline, respect for authority, listening and following directions, and as an added bonus – it’s “cool.”

In the three years that CIP has been providing fiscal intermediary and employer of record services, we have learned or been reminded of several important lessons:

- Supporting a family member to live in the community with an individually-designed and managed plan is hard work. Our approach has been to make things as easy as possible for the families. We have made extra efforts to be sensitive to the situations of families who experience additional challenges of underemployment, poverty, language barriers, and the cultural differences especially evident for families who have moved here from other countries.
- The language of formal supports can easily “spill” into supporting consumer-directed options. Words are very powerful, and we have made conscious efforts to carefully consider how we talk about what we do. We support “families,” not “clients.” We “get together with families” rather than attend a “staffing” or “team meeting.” We don’t do “intake.” Families are not “admitted” to our program, nor are they “discharged.” We work to be approachable and sound friendly – and the feedback we receive indicates that people appreciate our efforts.
- Consumer directed supports are not licensed services. Any protocol that would be automatic when developing a traditional program was reexamined. For example, most programs will have a new participant sign a Bill of Rights acknowledging their understanding of certain protections for recipients of licensed services. Since consumer-directed supports are not licensed services, we do not have participants sign a Bill of Rights; not only does it seem to us to be unnecessary paperwork, it also seems a bit odd to ask a parent or legal representative to sign such a form. As one family member told us “I’m not to require my mother to read a three-inch stack of training materials and sign dozens of forms so that she can take care of her grandson.”
- This is not our money. We are not receiving a “rate” for a “unit of service provided.” We are simply processing the funds to assure that they are legitimate, approved expenses. It is not our role to question whether or not the family should be able to pay for vacation expenses for direct support staff to accompany the family for a once-in-a-lifetime trip to New York for a family reunion. If it was in the plan, and the plan was approved and authorized, we will pay it.
Consumer-directed community supports (CDCS) is a service option offered in Minnesota through the Home and Community-Based Services Waiver for Persons with Mental Retardation and Related Conditions (HCBS/MRRC). Hennepin County, which includes the Minneapolis metropolitan area, was one of the first counties in the state to partner with the Minnesota Department of Human Services to offer CDCS. This service option can be described as:

- A program in which individuals and families use individually-set budgets to purchase their own supports, with assistance from fiscal intermediaries that handle billing and payment.
- A part of the HCBS/MRRC, which requires supports to be habilitative (i.e., designed to support progress toward outcomes) and meet other standards.
- A program in which functional outcomes guide the services and supports a person uses, within the general rules of the HCBS/MRRC program.
- An option that empowers many families and individuals with more choice and control over their services and outcomes.
- A nationally accepted model of service delivery considered a best practice and future direction in the long-term care arena.

Hennepin County’s involvement in CDCS for persons with mental retardation and related conditions began following a heavily attended 1997 community forum called New Values, New Visions (Hennepin County, 1997). Feedback at this forum, as well as subsequent focus groups with community members, indicated that county residents wanted more flexible, consumer-driven supports that offered people more choice and control over their supports and services. This vision propelled the County to enter into a Memorandum of Understanding with the Minnesota Department of Human Services in 1999 to offer CDCS.

The County is now a nationwide leader in the provision of CDCS. Currently, 43% (1346) of the people who receive HCBS/MRRC in the county use CDCS. Slightly more than half of these recipients are under the age of 18, with the average age at 19, and most CDCS recipients live at home with their families. In part due to how well it has been received in Hennepin County, the consumer-directed option is being expanded statewide for persons with mental retardation and related conditions as well as to other persons with disabilities.

How and Why Hennepin County Committed to CDCS

Hennepin County had been moving toward a commitment to self-determination and individually-controlled budgets for many years before CDCS became an option under the HCBS/MRRC program. In a variety of ways, it had worked toward shifting the roles and responsibilities of waiver recipients and social services staff. For example, from 1997 to 2000 the County worked closely with three other Minnesota counties (Dakota, Olmsted and Blue Earth) on creating more person-centered and consumer-directed services as part of the Robert Wood Johnson Foundation Self-Determination Project. Along with them, Hennepin County participated in national and local conferences and training events regarding self-determination. As part of its commitment the County hired personnel specifically assigned to the development of a model for individually-controlled budgets. Supporting this commitment and easing the process were internal champions and a community advisory group committed to making self-determination and increased control a reality for people and their families in Hennepin County.

There have also been several pressing problems that helped move the County and its service recipients toward CDCS.

As in many places throughout the United States there had been a significant staffing crisis in this area. Traditional service providers often simply could not find and keep enough approved staff to meet the needs of the people to whom they were currently providing services. The reluctance of existing service providers to expand, coupled with a large waiting list of families and individuals needing services, resulted in a significant staffing crisis in the 1990s. CDCS has been an option to resolve this crisis by allowing families greater flexibility and direct participation in the staff recruitment and hiring process. This flexibility and direct participation has offered an opportunity to expand the pool of service providers to individuals who may not have otherwise provided services to individuals with disabilities in the county.
**How CDCS Works**

Under the CDCS option, Hennepin County’s role in the life of the individual receiving services has shifted from that of purchaser of services to more of a support function (see Figure 1 describing the roles of various stakeholders). However, the County retains some basic accountability related to assuring quality and equity. Although the program is consumer-directed, there are some components for which state and federal regulations require the County to be responsible. Additionally, the County retains administrative responsibilities that exist under the HCBS/MRRC program, such as determining eligibility and managing the overall waiver budget. The Memorandum of Understanding between the State and Hennepin County highlights a number of areas for which the local County agency is responsible. Examples include:

- Provide general information and assistance to families about the program.
- Review and approve the community support plan, and monitor and evaluate its implementation.
- Review expenditures regularly.
- Provide additional technical assistance if it is determined that the recipient is not following the community support plan (including corrective action plans) and, when necessary, discontinue CDCS after required notification.
- Investigate, provide notice and suspend CDCS if there are immediate concerns about health and safety or misuse of public funds.

CDCS has been a remarkable option with many positive outcomes for individuals and families, including:

- CDCS offers excellent flexibility for families by allowing them to select staff that they know and trust. This is especially important for Spanish, Hmong, Russian, American Indian, and other minority families. They have been able to hire staff who meet their needs for language interpretation and cultural sensitivity because they draw on their own community for staff rather than traditional provider agencies that may not have a presence in that community.
- Families are able to compensate staff more flexibly, within guidelines, and reward the skill and diversity that staff bring to their work.
- CDCS offers the opportunity for individuals and families to create services that are more responsive to specific needs within established guidelines. For example, an adult recipient who moved into a townhouse was able to access trusted and consistent supports for his specific needs while enjoying a natural home setting because of the flexible nature of CDCS.

When problems and challenging behavior arose, staff and supports were reconfigured to meet the individual’s needs instead of the individual being asked to meet the expectations of the licensed agency.

[Mellum, continued on page 31]

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**Figure 1: Roles of Stakeholders in CDCS**

**Family / Person Receiving Services**

- Develop a community support plan that indicates the plan for hiring staff, activities and other supports, and what the outcomes will be.
- Describe staff qualifications and a plan to address health and safety.
- Hire and supervise staff (which can be neighbors, family, friends, or people identified through advertisements or other recruiting); select and hire a fiscal intermediary agency.
- Submit to the fiscal intermediary timecards and documentation of activities in order to be reimbursed.
- Annually report progress on outcomes to the county.

**County**

- Inform people about CDCS as a service option and provide options for hiring fiscal and support agents.
- Authorize services listed in plan in state management information system.
- Perform quality assurance activities including review support plan to ensure it complies with waiver requirements, annually review progress on outcomes identified in support plan, problem solve, identify inappropriate use of funds, ensure health and safety, and gather and respond to consumer satisfaction feedback.

**Fiscal Intermediary**

- Help family develop financial component of plan and ensure it is within individualized budget amount.
- Review timecards and documentation of expenditures from families.
- Bill the state system for waiver services, pay staff and reimburse families for expenses.
- Notify the County of any concerning activity.

**Support/Coordinator Agent (if hired and as requested by the family)**

- Help develop support plan and develop staff job descriptions.
- Help monitor spending to stay within budget.
- Help supervise staff.
- Other assistance with plan monitoring and implementation, as requested by family.

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Fighting for Richard: A Mother’s Story

by Bonnie Jean Smith

I am Bonnie Jean Smith, a mother of four children, and I’m here to share with you my experience of living with autism and participating in the Consumer-Directed Community Supports (CDCS) program, a service alternative available in our home state of Minnesota through the Home and Community-Based Services waiver and Hennepin County, where we live.

I have three sons: Donny, 15; Richard, who is 13; and Ryan, aged 9. Two of my sons are on the autistic spectrum and were affected by lead paint dust exposure as infants. My daughter, Danielle, is 18 and, although still connected with our daily family life, she is no longer living at home. Being raised by both parents, I did not set out to be a single parent. When my partner got stuck in a mid-life crisis, it became clear that I needed to take on the challenge of parenting alone.

The whole country learned about autism through the movie Rain Man. Dustin Hoffman’s character had obvious difficulty in getting along with people, but he was brilliant in the memorization of numbers and lists, and in calculating dates. This was an introduction to autism for many people, but there is so much more to be known about people with this disability. I would like you to get to know Richard, one of my sons with autism, who is a participant in the CDCS program offered through Hennepin County.

About eight years ago, I decided to start a fight for Richard so that he would be more than a professional’s label. As a loving mom, I knew him well from watching him closely. I had observed too much about his potential to accept that he should become neatly defined as an “Emotional Behavior Disorder Student.” Richard is complex, and in that complexity are the following characteristics related to autism:

- Richard needs to have life ordered and predictable.
- Richard’s circle of trusted friends is very small.
- Richard’s high anxiety reaction to the disorderliness of life is to run – to quietly turn and leave.
- Richard learns differently than many others – he is a visual learner.
- Richard, like other autistic people, has one “genius level” talent that is almost beyond comprehension.
- Richard cannot handle over-stimulation, such as loud sounds or excessive lights for long periods of time.

Need for Order and Predictability

Autism means that Richard needs to have life ordered and predictable. Daycare was a good environment for Richard as a young child because it was orderly with clear transitions; there were no surprises – snack, naptime, playtime are very scheduled. His orderliness extended to consistency and fairness in how people were treated; when toys were not shared, Richard spoke up for fairness and everyone taking their turn. Orderliness was important to him. As you might expect, the school environment he entered as he got older was less orderly and predictable. It included the unexpected teacher, new books that didn’t come when promised, schedule changes because of emergencies. This lack of orderliness reached a breaking point for Richard in first grade. Since then, I’ve tried to find and use all the resources available to us to advocate for his needs. As one resource, the CDCS program has helped lend order and predictability to his environment in a number of ways. For example, routine is important to Richard and part of his routine is that he likes to go outside alone early in the morning; so through CDCS we were able to get a six-foot high fence put around our yard, which enables him to be outside every morning by himself and stay safely at home. Predictability in his relationship with his sister is also important; after she grew up and left home, we still needed to maintain her room in the house because Richard insisted that Danielle had not left home and the presence of her room helped meet the need for her predictable presence. The way that the CDCS program has helped Richard stay connected to his sister is by making it possible for Danielle to work as the personal care attendant for Richard; so even though she doesn’t live with us, she is still a regular part of his life.

A Small Circle of Friends

Autism means that Richard’s circle of trusted friends is very small. He trusts me, his brothers, his sister, and Aunt Bernadette. Beyond that the circle is small. When he doesn’t trust someone he might show this by never learning that person’s name or letting him or her sit alongside him – he will stand or have the other person stand. When Richard lets me know why he does not trust that person, often it is because he has noticed some unfair behaviors on their part.

The CDCS program makes it possible to hire and retain good people who Richard trusts to guide him and help him be his best. In addition to hiring his sis-
ter as his personal care attendant, his neighborhood “auntie” has been hired for respite care. It works out perfectly and I know these trusting relationships have been the reason for Richard’s sense of comfort and success in many areas.

**Anxiety Responses**

The high anxiety reaction Richard has to the disorderliness of life is to run. He just quietly turns and leaves. I call him my “runner.” In fourth grade, in response to not feeling safe, he walked 20 blocks away from school. A kind, elderly couple tried to help when he was “stuck” in their front sidewalk. When they approached him he held up his hand and said, “Stop, you are a stranger and I am lost.” He reached us on their cell phone and when we arrived he was being served cookies and milk from a safe distance. After this experience, the school and I trained Richard to find a safe way home.

To help Richard relax and manage anxiety, a trampoline and massage pad were purchased through the CDCS program. We also have a bicycle with flat tires to give him some exercise but to keep his speed down so I can keep up with him. To keep him safe and lessen my anxiety, high locks on the door and windows, an alarm system, and the six-foot-high fence were installed.

**Visual Learning**

Autism means that Richard learns differently than many others. He is a visual learner, which means that he communicates and learns through pictures. For example, to help him understand the value of washing his hands we got on the Internet to see pictures of germs and what happens when you wash your hands. Now he understands why. The CDCS program made it possible to purchase a computer, digital camera and bookbinder that enable Richard to find pictures on the Internet, take photos himself, and make his own storybooks that help him learn. We have built a reference library from his work. We have also made books to help him communicate. The pictures he took of the neighbors along with his interviews were turned into a book. One book, “Richard Saved the Flower,” came about when he realized that flowers would die with the cold weather. When Richard’s successful pumpkin seeds took over our garden the story, “Richard’s Pumpkin Patch” was told.

The FAST FORWARD program, software resulting from 25 years of brain research, was purchased through the CDCS program. What on the surface appears to be a video game is actually a learning assessment tool. I start the game with a sign-in and then let Richard play to his heart’s content. Afterwards, I will put in the password and get a print-out assessment of his learning, which I hand over to Richard’s teacher. The software identifies the “holes in his learning.” Over a three- or four-month period Richard’s reading skills improved two to three grades. It was an invaluable tool for the teacher to help Richard succeed.

**“Genius-Level” Talent**

As in *Rain Man*, some autistic people have one “genius level” talent that is almost beyond comprehension. Richard excels beyond belief in choreography, music, and art. He is enrolled in the American Variety Theater Company through the CDCS program. They have provided special lessons, tap shoes, and shiny, satin performance clothes. When he is on stage, he shines. The first time I saw him he performed with confidence and stunned us all, especially me. Richard earned the Sammy Davis, Jr. Tap Dancing Award. “I’m really good! I’m really good!” he said. In that setting he is treated as any other child, placed in leadership roles, and expected to succeed in the competitions.

**Sensitivity to Over-Stimulation**

Autism means that Richard cannot handle over-stimulation, such as loud sounds or excessive lights for long periods of time. In the American Variety Theater talent contest, Richard and his brothers won *NSYNC concert tickets. He knew he could not hold it together for the length of the concert – he mentioned to me the loud noise, the screaming girls, that he would have to leave and make his brothers and sister leave with him. He decided that it would be better to give his ticket to his sister’s friend. Instead, Richard and I spent the evening together while he skateboarded in the community. When I heard him show this self-awareness I said to myself, “Hey, there is growth – like a light bulb!”

**Breathing Room for Mom**

My Richard is a Pandora’s Box for me. I never know what challenge is coming next. Prior to the CDCS program, I went sleepless and became depressed due to the constant monitoring that he needed. Richard was a “wind up toy.” Without medication he could function on one hour of sleep a day. With the breathing room given to me by personal care attendants and these common sense tools I have been talking about, I now can see that he is a visionary and a pioneer that has led me into a new universe. He sees, feels, and senses things that many of us easily ignore or discard. He has taught me the difference between real needs and perceived needs. My goal is to continually explore the ways in which he will gain self-confidence, learn more daily life skills, and feel appreciated for just being Richard.

I am continuing on my quest to help others see what I see in Richard. I want others to see an incredible person with talent and strengths and sensitivities. My challenge is to continue to guide this young man with values and a sense of what is right and wrong. I know his skills and talents will definitely make a positive contribution to our community.

Bonnie Jean Smith is a parent and participant in the Consumer-Directed Community Supports program in Minneapolis. She may be reached at gap55411@aol.com.
The Vermont Way: Evolution of Consumer-Controlled Budgets in Vermont

by Pam Walker

The values of a community or group of people permeate and influence what they do, including how their service systems operate. People in Vermont think of their state as a place where people share certain values with respect to “taking care of one’s own” and because it is a small state, people have relatively close contact with one another. The state of Vermont has long been a leader in providing individualized supports and in efforts to increase consumer control and choice. Since the Medicaid waiver was enacted in 1981, the state has chosen to use this funding stream to support people in individualized ways, rather than using it to fit people into programs. Thus, for over 20 years the state Division of Developmental Services has used individualized budgets, which allow for money to follow the individual for people funded through the Medicaid waiver. In the past, this contributed to Vermont’s ability to close its state institution as well as to develop largely individualized rather than congregate, facility-based services. In addition, having a designated provider system (which includes 10 designated agencies and 5 specialized service agencies) has required that all individuals, regardless of the severity of their disability, be served by community providers in their local region. As Theresa Wood, Director of the Division of Developmental Services, commented, “The designated agency system ensures a community safety net for people with the most significant disabilities.”

During the 1990s, there was a growing realization among many stakeholders — including self-advocates, families, the Division, service agencies, and others — that individualized budgets were not sufficient, and that there was a need for more options for choice and control by people with disabilities and families. The Division and collaborators applied for and were awarded a three-year grant (1997-1999) from the Robert Wood Johnson Foundation to implement the Self-Determination Project. Among other things, the project provided resources to move from individualized budgets to consumer-controlled budgets. In particular, the project assisted with research on the use of ISOs (intermediary service organizations), development of the ISO as a tool, and provision of training and information to people about their choices.

To receive services, an individual must apply for services, after which an eligibility evaluation and needs assessment are done, and a funding proposal is submitted to a local funding committee. If the person’s needs line up with a system-of-care plan funding priority, the person receives funding to meet that need. They then have the option of self-management, family management, agency management, or shared management of services. Each designated agency must have an individual who will assist the person in whatever choice they make.

Consumer control gives individuals greater flexibility around who works for them, when the person works to support them, and exactly what the job description is. Ms. Wood has observed, “It’s very personalized and staff are accountable to the person, not an agency.” She has further noted, “Being in charge gives people with developmental disabilities the same things that it gives anyone – a sense of power, of being in control, and of being able to prioritize things that are important.” In this way, in general, resources get directed in better ways. At the same time, however, consumer control requires involvement with payroll, timesheets, the ISO, hiring, firing, and training staff. Due to the amount and type of effort involved, it seems to work best when individuals and families have strong teams supporting them.

Consumer control is still evolving in a variety of ways within the system. For instance, even with consumer control people are still linked to service agencies. However, some people have expressed the desire for less connection to agencies. Through a Real Choice grant awarded by the Centers for Medicare and Medicaid Services, U.S. Department of Health and Human Services, to promote community integration and systems change, Vermont is initiating a pilot direct consumer funding project. In conjunction with this, the role of ISOs may be expanded to include involvement with staff hiring and firing, budget development, and so forth. In addition, the system is evolving so that individuals and families will be able to set their own budget based on the needs assessment. This option will start in 2004. Finally, through the Real Choice grant, there is effort to make the process of self-management less cumbersome.

At the same time that so much effort is being put into facilitating consumer control of budgets and services, there is recognition that everyone does not want to manage their own budgets and services. Therefore, attention has also been given to promoting evolution within service agencies that promotes increased choice and control. For example, individuals can write their own ISA (individualized support agreement), have access to detailed information about their budgets, and can negotiate regarding resource allocation.

The efforts to promote consumer control in Vermont have created many very positive changes for individuals, as well as for the system as a whole. At the same time, there are always challenges associated with change. One challenge is to continue to educate more people about the realities of consumer control. As Julie Martin, Director of Community Developmental Services at Washington
What Lisa Wants

Lisa* entered adult services in Vermont five years ago from a residential school. She lives in her own apartment, with staff support from 9-4 weekdays, and overnight five nights a week. For two years, she received her supports through an agency, where the agency hired and trained the staff who supported her. Over time, however, she began having significant difficulties in relationships with her support staff. These difficulties pervaded every aspect of Lisa's life, causing her to feel as though she had no control, which was expressed through sometimes violent actions and reactions. Through the agency, there were limitations on her ability to replace staff, and, overall, to feel a sense of control.

Lisa and her mother began meeting with a service coordinator at the agency to look for solutions to the problem. The result of these conversations was a shift to consumer-controlled services three years ago. The agency still plays a role in Lisa's services, primarily one of limited liability, monitoring, and service coordination. An agreement was drafted specifying the responsibilities of the agency, and of Lisa and her family. This was the first time that such an arrangement had been created by this agency, but as the result of the pioneering efforts of Lisa and her family, in conjunction with agency staff, others have worked out similar arrangements since that time.

There have been many advantages of this arrangement for Lisa. With the assistance of her sister, who is also her guardian, Lisa hires her own staff. One of these staff people formerly provided support through the agency, and they had a good relationship. She has found other staff on her own. Overall, she feels very positive about her relations with her staff now. And, over time, she is learning how to manage her staff, including how to work on problems and issues that arise.

When supports were provided through the agency, there were limitations on Lisa's control of her time and activities, on times when staff were available, and on the mileage that staff could charge for providing transportation. With this consumer-controlled arrangement, Lisa has the opportunity to make more decisions about use of staff time. In addition, she can hire staff for whatever hours she needs and can reimburse them for whatever amount of mileage that she needs.

Lisa always had close ties to her family, something that is very important to her. However, her sister feels that working on this together with her family has given Lisa an even greater sense of connection to them. Overall, Lisa is very satisfied with this arrangement for services, and having this sense of control has positively affected her entire quality of life. She says, “Things are better now. I like having control over who works with me, and having choices about relationships with my friends and boyfriend.” As her sister put it, “Her life used to be more about what staff wanted; now it is more about what Lisa wants.”

*Note: pseudonym

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Contributed by Pam Walker, Center on Human Policy, Syracuse University, Syracuse, New York
Those living without a label take personal decision-making for granted, yet the right to self-determination has been denied to individuals with disabilities and their families by services that lack accountability and flexibility, and which ultimately reduce people’s citizenship status. The reasons are complex, but even a cursory analysis reveals a disability system that is predicated on two key, yet outdated, mechanisms: block funding and case management. New approaches must honor self-determination and accommodate people’s aspirations. Individualized funding (IF) and independent planning (IP) have major roles in this transformation: both promise people with disabilities and their allies control over their lives.

IF refers to public money allocated to individuals, or in the case of children to their parents, to meet disability-related needs. With IF, the person or family determines how funds are spent, within agreed parameters. However, informed decision-making requires more than economic power. This is where IP fits: information, advice and technical assistance provided to those requesting support to identify different ways to meet personal needs. With IP, practitioners cross various boundaries to assist people to achieve their vision of a good life.

IP began in 1976 when a British Columbia parent group conceptualized the service broker as a professional, independent from funders and providers, who could assist their family members to return to the community from an institution. Where are we, 27 years later? Simply put, conflict-free planning led by individuals and families exists on the periphery. IP certainly hasn’t supplanted case management, and is unlikely to. While case managers continue to reinvent themselves, they remain agents of the state. Inevitably, when an innovative idea emerges, people try to understand it in terms familiar to them; the result is that the essence is lost, and the idea becomes downgraded to a new variation on an old theme. So, we are left in a quandary. How, in a complex environment with competing agendas, do we move IP beyond its “boutique” status and embed it as a new system element? This article outlines what British Columbia advocates are now doing to achieve that outcome.

System Change in British Columbia

British Columbia was the first Canadian province to close its institutions and has a history of service innovation. Yet, the current system, governed by the Ministry of Children and Family Development, has fallen short of meeting individuals’ and families’ expectations. The system is characterized by both government and community as reactive and financially unsustainable. In a unique partnership, a community coalition has been working with government planning the creation of a new community governance body to be known as Community Living British Columbia (CLBC). CLBC will be created by the Community Living Authority Act and will assume responsibility for all services and supports provided to adults with developmental disabilities, and children with special needs and their families in late 2004.

CLBC, which will be committed to the people it serves having the opportunities and supports needed to pursue their goals and participate as full citizens, will have three primary roles:

• Provide community level assistance, including independent planning support, to individuals and families who receive, request or require community living support.

• Manage the means of providing support to people who require services.

• Stimulate, encourage, and support community level innovation and creativity to change how communities respond to people with a disability.

A key element of change is Independent Planning Support (IPS), which CLBC will define as the provision of information, advice, and procedural assistance to eligible individuals and families, independent from service providers and service funding decisions, to assist them in developing and implementing their personal support plans.

To achieve its vision, CLBC will have two separate divisions, each headed by a vice-president: Community Operations, and Planning and Community Development. Community Operations, located centrally, will be responsible for system functions like eligibility determination, resource allocation, contract management, and outcome reporting. Planning and Community Development, operationalized through staff known as Community Living Facilitators, will provide IPS and engage in community development activities.

CLBC will be governed by a nine-member “Carver style” board which will include self-advocates and family members. The draft legislation specifies CLBC “must” provide both IF and IPS. The bifurcated organizational structure is an attempt to “firewall” IPS from operational decisions involving eligibility and funding. These gate-keeping functions have historically hindered the provision of community-level planning support needed by individuals and families. In designing CLBC, advocates had to accommodate government’s position that it wouldn’t support creating two separate legal entities, one of which would provide planning.
Independent Planning Support – A Key Role in the New System

Community participants in the planning process set out to change the way communities respond to people with disabilities. IPS, with its focus on flexible and innovative ways of providing support, is a fundamental element of the plan. Facilitators will have a “community first” focus geared to “empowering and supporting” individuals and families in ways that they determine are important to them. Planning will be directed always by individuals and families. Role separation will also increase job satisfaction and stimulate professional creativity that leads down a different path:

- Towards flexible supports targeted to meet individual needs.
- Towards supporting people to make decisions that maintain independence.
- Towards effective use of flexible, individualized funding.
- Towards greater community involvement in developing appropriate, cost effective, and sustainable person-focused solutions.
- Towards cooperative planning that takes advantage of existing community capacity and that excites an interest in creating new capacity.

British Columbia is moving from five macro regions to the concept of 17 community areas, and from 51 offices in 40 communities to staff who are resident in 55 communities. Facilitators will work out of, or be affiliated with, one of 17 Community Living Centres which will also serve as meeting places for individuals and families to share ideas and access information. Facilitators will be mobile, using advanced technology to stay connected.

Although facilitators will be operationally independent from CLBC decision-making processes, they won’t be fully independent. However, various safeguards have been created. A Community Living Planning Commission will act as a “watchdog” to ensure CLBC delivers IPS to the community’s satisfaction. A charter will set out facilitators’ roles and responsibilities and the job description will outline facilitator accountability to individuals and families. People don’t have to use IPS; they can access planning support from those with whom they have trusted relationships.

Other changes are also occurring. A flexible individual and family support policy will establish parameters around how the system responds to individuals’ and families’ needs. Contracts will require agencies to report on personal and system level “outcomes,” rather than “inputs.” Communities will determine their own crisis response approaches, and there will be an array of safeguards, both multiple and redundant, formal and informal.

Conclusion

British Columbia’s community governance model blends vision and pragmatism and illustrates how a community-led transformation process can redress the resistance and inertia which characterize bureaucratic human service systems. The model invests considerable resources in the facilitator role in the hope this will contribute to greater system-level innovation and creativity, and better individual and family outcomes. It isn’t a perfect system, but the risks are worth it. British Columbia’s system change initiative remains a bold attempt by community and government to create a foundation upon which people can begin to reclaim their citizenship rights.

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Resources on Systems Change

Supporting Consumer Control


- www.cms.hhs.gov/promisingpractices. The Promising Practices in Home and Community-Based Services Web site operated by the Centers for Medicare and Medicaid Services, U.S. Department of Health and Human Services, includes a series of reports on home and community-based services to assist states, in partnership with their disability and aging communities, to strengthen their community long-term support systems.

- www.hcbs.org. The Community Living Exchange Collaborative Clearinghouse Web site facilitates sharing information, tools, and practical resources across states and local entities that are re-examining and re-designing how they provide supports.
[Perry, continued from page 1]

started CDCS about two and one-half years ago. So you can better understand how important CDCS is to me now, I will tell you a little bit about what my life was like during the 27 and one-half years before CDCS.

I was born on October 27, 1973 in Bloomington, Indiana. It wasn’t until I was 16 years old that I was diagnosed with a disability called autism. Before that I had been given lots of labels—retarded, developmentally disabled, bi-polar, schizophrenic, emotionally-behaviorally disturbed, to name a few. During the first 18 years of my life, I lived with my parents and received no specific services for my disability from an outside agency except for at school I was always in special education. A lot of people did not know what to do or how to provide services for me. It was extremely stressful for me in school, especially in high school. I didn’t get along with kids. Most of them made fun of me because of my disability. And I watched everybody else grow up and have friends and have relationships while I felt abandoned. I’ve never really had friends. One positive thing during that time was that some neighbors would help me with some of the difficulties I was having.

When I was about 17 I was kicked out of school because of my “behavior.” I had to move out of my parents’ home and into my brother’s, and we fought the school to get me the education I had a right to. At some point I did start receiving some services like help with finding and keeping a job, finding friends, joining a scuba diving club, getting an apartment, and learning how to live with a roommate. While the staff persons were helpful for the most part, many of them would resign and not stay with me for very long. That caused me tremendous stress. Also, most of the staff was not very educated and they didn’t really know how to support people with autism who have challenging behaviors.

With all of my bad experiences with services and direct care staff over the past 10 years, I was very excited to hear about the CDCS option and the possibilities of getting the support I wanted so my life would be happier and I could make my own decisions. One of the first actions that I took with my family and support people after being approved for the CDCS option in Minneapolis was to develop a person-centered plan. It took us several meetings to gather all the information that we needed to complete a plan that we all liked and agreed on. Here are the parts that make up that plan:

- A mission statement for me and my support team.
- A list of my hopes and dreams for the future.
- A list of my strengths and limitations (knowing this helps my team provide good supports).
- A description of the goals, action steps, list of people to help me reach the goals, a timeline to help us all stay on target, and resources we can use.
- A set of qualifications for staff to be part of my support team.
- A description of team member responsibilities for carrying out my personal support plan.

After writing my support plan, we spent some time talking about and writing a job description for the staff who would work with me. We also wrote my Employee Policies and Procedures Manual. Using this manual made it easier to find, interview, and hire well-qualified staff who could support me in reaching my goals, hopes, and dreams. My employee manual has the following parts:

- My team mission.
- My vision and dreams.
- My expectations of the roles direct support professionals have who work for me.
- Specific policies and procedures related to: minimum requirements and considerations for being employed by me; the areas of needed and desired training; expectations about confidentiality, respect, and privacy for me; requirements for documentation and human resource areas (e.g., mileage and expense reimbursement, salary, paid time off, incentive bonus, etc.); expectations about participation in support team meetings; and the use of positive discipline.

- Staff training checklist.
- Responsibilities for me, the direct support professionals (DSPs), and other professionals in carrying out my personal support plan.
- Desired characteristics and qualifications for my support team members.

What I did next was to look at who I knew that might be good DSPs to be a part of my support team. We discussed a number of possibilities (people who we knew were already working full- or part-time as DSPs in different work settings), contacted them to ask about their interest in supporting me, interviewed those who were interested, made decisions about who we wanted, let them know about our decision, and later conducted an orientation session with each of them. Now, we have been working together for about two years.

When I think about the CDCS and what is working the best for me, I have a number of points I can make. First, I want to say some things about my staff. All my staff have been very helpful to me. They really know my moods and how to work with me; they listen carefully to what I say, help me make better decisions, and challenge me when I need it. All of them have been available to me when I have one of my crises. Then, they help me to focus my thoughts and actions and to emphasize my strengths. A couple of other things I know about the direct support professionals who work with me are that they have made my life more stable, and over the past two-plus years only one staff person resigned and that was due to some personal situations, not because they didn’t want to work with me anymore. Also no one has broken my “not showing up and not calling is not acceptable” rule for staff.
working with me. All of the staff told me individually or in support team meetings that the CDCS means less paperwork, no office politics and almost no agency bureaucracy for them...and for me and my family. They also have said that they are happier and more satisfied as professionals working with me in the CDCS than with many of their other jobs as direct support staff. What has worked best for me with the CDCS option is that I get to do what is important to me and not what others think I should be doing. Some other things that work for me are:

- I am connected to more people, events, clubs, and churches, etc. in the community than ever before.
- I am eating somewhat more healthy foods and doing more exercise on at least a semi-regular basis.
- My independence is so much better; I go where I want, when I want.
- I have spent more fun time with Amos (my nephew) and enjoy being at the family cabin in Wisconsin.

With all these good things in my life, you may think that every thing is wonderful and that I don’t have many problems or challenges that bother me. Well, I still do have lots of situations that can sometimes make me very frustrated, pained, sad or angry. One of the most difficult things recently is that I lost my job. It’s hard on me because I need the money to pay my bills and buy things that are important to me. Also, I miss some of my co-workers and I am sad that this is a job I have had the longest in my life, about three years. We are working to hire a job coach and developer to help me find another good job, or even a career. Here is a list of some other challenges and struggles that continue to be part of my life:

- Living in a small apartment attached to my brother’s home has had its difficulties, like I have less privacy than I would have with my own apartment and sometimes I feel like my activities and “comings and goings” are monitored too closely. Increasing my independence and privacy by getting my own apartment is a key goal of mine.
- Having friends who are not my support staff is still not happening. I have a hard time starting a friendship and then keeping it going.
- Healthy living (less sleeping during the day, regular exercise, nutritional meals, and not talking so much to certain people who make me stressed out) is really hard to do all or most of the time.
- Working on my challenging behaviors (unhealthy boundaries with others, making a small irritation into a big frustration, being disrespectful by saying crude things or making sarcastic remarks) needs a better effort on my part.
- I don’t have a job or a career.
- I still have trouble with family dynamics.

WOW !! That’s a lot of challenges. But with the CDCS option, I have learned to deal with these difficulties in my life. At least I keep trying.

One more thing I want to talk about is what information I could share with other persons with disabilities and their families who might want to consider using the consumer-directed community supports option to manage their lives. Some of the things I would suggest include:

- Talk to your case manager (service coordinator) if you really want to use the CDCS or similar option, and keep talking to them until you get what you want.
- If you want more control over your life, think about using CDCS or a similar option; you can become more independent.
- With CDCS, I think you will have a higher probability of finding direct support professionals who are more educated and experienced. They seem to be able to help you more.
- I believe the CDCS or similar option can get more money for education and training to improve lives – both yours and your staff.

- I would suggest that you use an agency (called a Fiscal Intermediary or the Employer of Record) that can do the payroll, keep track of vacations, get the right kind of insurance, and so forth. Doing that yourself or through your family can be a real headache.
- Use your money you get for services wisely – pay staff as much as you possibly can, and if they need health benefits make sure they get them. Also, give them an incentive to do what you want them to. I pay staff a 20% bonus on their gross earnings if I achieve what I want each year.

Although sharing my stories and ideas with you has had some tough moments, especially about my past, I have enjoyed telling you about my life with CDCS. If you want to learn more about my life with the consumer-directed community supports option, or talk about my support plan or my employee policy and procedure manual, you can contact me.

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States must actively pursue strategies to assist people with disabilities and their families to develop a good understanding of the process used by their state to set the budget, assess needs, and allocate funding for supports.

while others separate statistically generated funding decisions from the process of selecting supports to meet identified needs. The final authority for approving individual budgets rests with the state in a majority of cases, followed by a county or municipal agencies, local committees or boards. People and families receiving support need to understand how the budgeting and negotiation process works so that they are able to receive the supports they need.

• Responding to Appeals and Requests for Re-Determination. The majority of states have policies and procedures for filing appeals. Not only should the individual budgeting process be understood by the person receiving support and his or her family, but people should also understand how to appeal decisions that have been made and how to access the training, support, and assistance they need to resolve differences or disputes that might arise.

It is Worth It

In most instances, individual budgeting represents a significant departure from the way services have been traditionally supported and requires changes at all levels in the funding chain from the state, county or designated agency allocating service dollars, to the individual or organization that provides the support. Individual budgeting and the other elements of self-directed services offer the means for people to design the supports they need as they see fit, determine for themselves the role service providers will play in their lives, and decide how the dollars that are allocated on their behalf will be spent. As individual budgeting options become increasingly available, states must actively pursue strategies to assist people with disabilities and their families to develop a good understanding of the process used by their state to set the budget, assess needs, and allocate funding for supports.

References


*Note: Person-centered planning refers to a variety of approaches to designing support plans for individuals with disabilities. Person-centered planning does not consist of a rigid set of requirements, but rather encompasses an array of values, principles and practices that function to tailor planning activities to the individual receiving support. Key tenants of person-centered planning include:

- The person is the center of any planning activities;
- The intent of person-centered planning is to assist individuals to live the lives of their choosing;
- The individual and those who know and care about him or her are the fundamental sources of information and decision-making;
- The individual directs the planning process that identifies strengths and capacities, desires and support needs; and
- Person-centered planning results in personally-defined outcomes.

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DSPs. Whatever format is used should include a balanced vision of the job from the DSP perspective and be provided before the job offer is made.

Referral bonuses are another intervention strategy that can yield employees who remain employed longer. This strategy uses referrals of potential new employees from existing employees. If the person referred is hired then the existing employee receives a bonus. It is often helpful to provide a small bonus at the time of hire and then an additional bonus (usually larger amount) at 6 months and 12 months. This encourages informal mentoring from the DSP who referred the new hire.

When looking for a new employee, it is important for individuals and families to consider the characteristics of their most successful and long-term DSPs. Once these have been identified then the individual and/or family should purposefully seek other people with similar characteristics. For example, if they consider their best employee to be a young, energetic recent high school graduate then they should probably recruit this type of new employee. On the other hand, if they consider their best employee to be a stay-at-home dad who works for the individual on a part-time basis, then they are somewhat more likely to be satisfied by candidates with similar characteristics. This is called purposeful targeted recruiting.

Once an individual or family has decided they have found someone they want to interview, it is important they have well-thought-out, behaviorally-oriented interview questions that solicit information and examples of specific skills. This intervention strategy is called structured interviewing. Interviewers should never ask a question that does not purposefully seek information that tells them something about whether the interviewee has desired skills and attitudes. For example, if it is important that a new employee be flexible, tolerant of ambiguity, energetic, and not fearful of snakes then it is equally important that interview questions be developed to learn the extent to which the interviewee meets these conditions.

Direct support professionals have a lot to learn about when they begin a new job, especially if they have never worked in a direct support role before. Individuals and families play critical roles in providing orientation and training to new employees irrespective of whether or not the employee is working for someone who self-directs or is working for an organization. Orientation is an opportunity to assist and support new employees in getting to know the person(s) to whom they’re providing supports, their new responsibilities, and other employees with whom they might be working. When working in a family home it is important to learn about the family dynamics and expectations and to begin to feel accepted. Training, on the other hand, is an opportunity for employees to learn new skills they will need to provide adequate supports to the person(s) they have been hired to support. These skills may include healthcare treatments and medication support, behavior support to prevent challenging behavior, the use of adaptive equipment, community activities and organizations in which the person is a member, and other tasks. Generally, individuals and families are often the best people to teach these skills; thus, people who self-direct often report that they appreciate being able to deliver their own training. But, it is also important that supplemental training be identified for areas in which the individual and/or family does not feel adequately prepared as a trainer.

Other important day-to-day interventions include those designed to motivate and recognize employees for doing a good job. These can be simple “thank you’s” or notes of appreciation. They can also include formal recognition activities such as nominating someone for a local award or writing an article for a neighborhood newspaper about their community contributions. Ultimately, however, creating an environment of respect and appreciation is critical to the satisfaction employees feel and therefore their commitment to staying in their jobs and doing their best. Individuals and families know first-hand how important DSPs are to their lives—perhaps this is a unique reason why individuals and families who self-direct often report higher retention rates of their employees.

References


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Joshua. For Joshua and his family JHI delivers his supports using the principles and tools of self-determination. But more importantly for Joshua it delivers freedom!

Joshua Golden is a survivor of our (traditional) support networks. By this I mean that our system has provided some type of supports since Joshua was eight years old. These supports never matched Joshua’s needs and often hurt him physically and mentally. We explored the SDSC model and often wondered, “Why can’t we become the provider?” We knew that the government needed their accountability, but Joshua needed control over his supports and our systems were taking too long to catch up with Joshua’s needs. So the SDSC was the answer.

How does it work? We have formed a not-for-profit, JHI, around Joshua and become the legal entity, as his agency, to receive Joshua’s allotted Medicaid dollars. Only people who care about and share a vision for Joshua serve (on a volunteer basis) on his board of directors. The board, committed to Joshua, assures that he receives services that match his needs, desires, and lifestyle. He is in control, with the assistance of people who want him to be successful.

What does this mean for Joshua? It means that he no longer has to deal with a system that doesn’t value him as a person. He can select who comes into his life as his support team. He is the director and decision maker, balanced with others who care about him. By now you are thinking that Joshua is a very able young man. That is true. And if you met Joshua you would realize that he needs care 24 hours a day, seven days a week and that he has significant cognitive disabilities. It is his support team, JHI, and his staff who recognize that Joshua is at his best when his life is filled with people who care and want him to succeed.

What does this mean for Joshua’s family? Joshua’s sister and his parents serve on his board, along with Joshua. The board also has five other board members, so Mom can be out-voted (as it should be), as it is Joshua’s life. The key is to have people with a vision and commitment who are willing to spend time with Joshua. It also means a support network for Joshua’s family. No longer is it only his parents looking to secure Joshua’s future. It is his legal board of directors that is working for him. Joshua’s sister now realizes that she will have people to help her with Joshua when his parents are no longer around; it is a support team for her as well.

We have been asked what it is like to have such an agency for Joshua. Our response is that while it is work, it is the most wonderful thing that has happened to Joshua and us. He truly can have a life that is his own and we can finally sleep at night, knowing that there are only people who care about him in his life.

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Resources on SDSCs and Microboards

- www.Microboard.org. This is the Web site of the Vela Microboard Association in British Columbia, one of the largest associations of microboards in North America. Its Web site includes many individual stories, calendars of events, brochures, links to other Web sites, and other information of interest and usefulness in understanding and replicating microboard concepts and practices.

- www.self-determined.org. The Self-Directed Support Corporation Web site provides an overview of principles and operation of self-directed support corporations (SDSCs) and answers frequently asked questions. It includes links to SDSC organizations and resources by state, and also provides links to other related sites of interest.

- www.moddrc.com/Information_Disabilities/TopicPages/M-LetterTopics/Microboards.htm. This section of the Web site of the Missouri Developmental Disability Resource Center features the Missouri Microboard Development Workbook, a very useful resource for microboard background and planning. The site also provides access to David and Faye Wetherow’s paper, “Microboards and Microboard Association Design, Development and Implementation,” an excellent introductory resource, as well as links to other helpful information.
The County has also collaborated closely with other counties as a means to establish consistency in the program.

Due to the rapid expansion of the CDCS option in Hennepin County, the County has at times needed to backtrack to build more effective systems of support and monitoring for the already-operating program. Certainly a slower paced growth of CDCS would often be preferable in implementing individually-controlled options.

Additional challenges have arisen when state government has adjusted funding that the County receives. In such situations, the County has had to struggle with how to allocate resources and resource reductions equitably.

Hennepin County continues to struggle with decisions regarding individual situations, including when people can and cannot continue on CDCS, and the need to balance standardization of allowable expenses and options under CDCS with the promise of flexibility and “freedom” in buying one’s own services. It remains a challenge to define and refine the role of the County with respect to monitoring, quality assurance, and fraud investigations. County personnel who have previously been decision-makers and in the role of gatekeeping and monitoring have had to change their ways of thinking. CDCS has provided opportunities for much discussion and education for all stakeholders.

Remainig Challenges

While Hennepin County has done remarkably well in moving into the CDCS option for people with mental retardation and related conditions and their families, it has not been a totally smooth transition. The shift in roles has meant that both the County and people receiving services and their families have faced a learning curve during the last several years. Many challenges have popped up along the way and many remain as the County moves forward with improving CDCS. When the concept of individually-controlled budgets and increased consumer choice and control was initially presented to County staff, there were concerns. A great deal of effort was put into researching models and establishing consistent procedures and guidelines. In this process, the County partnered with stakeholders invested in self-determination, and co-sponsored a Self-Determination Advisory Committee with Arc Hennepin/Carver. This group was comprised of service recipients, family members, service providers, advocates and County personnel and was organized around the principles of self-determination in all aspects of life. The group has been especially active and instrumental in contributions made to the CDCS program in Hennepin County. The County has also collaborated closely with other counties as a means to establish consistency in the program.

The Future of CDCS

As individuals with disabilities and their families using CDCS become more sophisticated, the case management role changes. Ideally, social work staff would be able to focus on people with greater or particular needs and on people with fewer natural supports, while those using CDCS function more independently. While CDCS offers many advantages for individuals and their families, Hennepin County, along with all stakeholders involved in CDCS, continues to identify and respond to issues that have not been faced in traditional service models. As consumer-directed options continue to expand across the state and country, it will be important for all stakeholders to learn from each other about effective ways to solve individual and administrative challenges.

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