Flexible Funding to Promote Integrated Services and Choice and Control

a report prepared by Maine's Work Group for Community-Based Living

Comprehensive, integrated services driven by individual or, when appropriate, family needs should be available to persons with disabilities. Funding for services should be flexible, responding to those needs and, whenever possible, permitting the exercise of individual choice and control over the services provided.

Findings

The current system for providing services is fragmented and uncoordinated, with access to services provided through multiple programs driven by different funding streams. The source of funding very often determines the way services are delivered and very often restricts the kind of services that are available and who can provide the services.

Self-determination, and personal choice and preference are essential elements of successful care. The individual or family that needs the services, not the person providing them or the state agency or program funding them, is in the best position to determine what those needs are and how they should be met. The service system should integrate services while supporting individual choice.

Fragmented Support or Care Plans. There are many individuals who have support needs in a variety of areas who want and would benefit from support plans that respond to the individual's or the family's full range of needs. The failure to account for (and meet) the full range of needs can undermine the effectiveness of any or all the other services provided. For example, a plan might include multiple services but if it does not address an individual's or a family's need for a stable, satisfactory place to live, or transportation to get back and forth to a job or to an appointment, the plan is incomplete and its effectiveness is sabotaged. The process of assessing needs and developing a plan too often is limited to determining eligibility for the services offered through a certain program. Ideally, a multidisciplinary assessment should be available, with consultation as necessary with appropriate ancillary professionals, to develop a more comprehensive view of individual need. The assessment process might include occupational therapists, speech/language pathologists, and physical therapists, and others.

Uncoordinated Services. For the most part, an individual or family that wants to obtain services must seek out those services through multiple departments or programs, sometimes through the private providers and sometimes through a state agency. For each program, the individual or family must find out if they meet the eligibility criteria for the program, go through a needs assessment, and participate in a planning process. The needs assessed through the assessment process and the services offered under the resulting plan are usually limited to those services paid for by the program that funded the assessment and planning process. A child or adult could go through six different assessment processes and come out with six different plans. That means the family or individual could be patching together an array of services across multiple programs, without anyone taking a comprehensive look to make sure that the individual's or the

family's needs are actually being met, that the array of services are coordinated and working together, rather than against each other, or that the services offered are not duplicating the services offered through another program.

As a result, many people are weighted down by uncoordinated and duplicative service plans. In the Integrated Case Management pilot study, the average number of agencies providing services to pilot participants was seven. One family was served by 26 individual providers.[1] It is no wonder that one focus group participant said "Having a disability is a full time job." [2]

It is unfortunate that some people suffer from the unnecessary duplication of services while others in need of services cannot receive them because there are no providers available. A more rational, coordinated, and effective use of resources may result in an increased availability of providers to meet existing unmet need.

Gaps In Services. In addition to lack of coordination between services, there are also gaps between services. There may be funding to purchase a wheelchair ramp or hand controls for driving a car, but no funding for their installation. There may be funding for rent subsidies, but no funding for a down payment or utilities. As a general matter, there are many gaps in services for persons transitioning from one setting to another or from one program to another.

For persons transitioning out of an institutional setting, there are gaps in services to aid in that transition. Except for 30 days before discharge, federal law prohibits Medicaid payment for case management services as delivered by community providers while a person is still in an institutional setting, and yet those services can be critical in ensuring a successful transition to the community. In the context of a nursing facility transition, transition services should include an independent living assessment, case management services, assistance seeking housing arrangements, the purchase of assistive technology prior to the move, and peer support.[3] These aspects of service delivery are not funded. Without funded transition services, an individual interested in moving out of the nursing facility depends on nursing facility personnel to assist in the transition. Often nursing facility staff have no vested interest in promoting the transition work and may even oppose or undermine this planning process, although some believe nursing facility staff could provide beneficial support if engaged in transition efforts.[4]

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[1] Spence, R. (2000) *Maine Children's Cabinet: Integrated Case Management Initiative assessment report.* Edmund S. Muskie School of Public Service: Augusta, ME.

[2] Ormond, C., Ziller, E. and Richards, M. (2001) *Living in the community: Voices of Maine consumers, a report of findings from focus group discussions*. Edmund S. Muskie School of Public Service: Portland, ME.

[3] Funded through the Robert Woods Johnson grant under the Home to Community Project, Alpha One provided transition services necessary for a successful move. As a result of this effort, 26 individuals with disabilities moved from the nursing facility into the community. To date 18 of these people have remained out of the facility and continue to live more independently within the community. (For this small group of people, the combined monthly public expenditures for Medicaid, housing, transportation, food assistance and fuel assistance were lower in the community than Medicaid expenditures in the nursing home prior to moving.) Saucier, Bolda, Richards & Keith, *Evaluation of Alpha One's Independent Living Center's Home to the Community Demonstration Program*, (June 2001).

[4] Saucier, P., Bolda, E., Richards, M., and Keith, R. (2001) *Evaluation of Alpha One's Independent Living Center's Home to the Community Demonstration Program*. Edmund S. Muskie School of Public Service: Portland, ME.

For people who experience long-term psychiatric hospitalizations, transition services can also fall short when reintegrating into the community. Because of difficulties in funding the community support personnel's participation in hospital planning and due to difficulties in simple coordination with hospital treatment personnel, transition planning for needed community services can be inadequate.

Limited Choice over Provider. For some people, the right to decide who will provide their services is also limited. For example, a person might have no choice over who provides intimate personal care services; or an individual might have no choice among psychiatrists. Frequently the principles of choice and self-determination are in conflict with the interests of the people responsible for developing care plans or providing services. Putting choice and control in the hands of the consumer can mean that providers are not assured that their services will be used. However, a constructive way for providers to respond to market pressures created under these conditions is to be more responsive to consumers, providing services that are relevant and appropriate.

Limited choice can be built into the way services are delivered. For example, housing and other supportive services for individuals with psychiatric or developmental disabilities are still overly oriented to the "one-stop shopping" model, where a single agency acts as a landlord while also providing case management and even psychiatric services to residents. One-stop shopping occurs in both supported apartment and group setting models. The ability for individuals to exercise choice is limited not only in fact by reason of reimbursement mechanisms in some instances, but also by the policies of some agencies. The momentum of convenience for the provider often unwittingly diminishes choice and very often the individual using the service, whether rightfully or not, perceives risk: that to exercise the choice to seek out a separate provider for one aspect of service, would mean that they would lose all others.

In other cases, restrictive or inconsistent rules can arbitrarily impact choice of providers. For example, federal rules prohibit payment to spouses for personal care services. Persons with disabilities receiving personal care assistance under Medicaid cannot hire a spouse to perform the personal care services, while a person enrolled in the state-funded program can. When a person transitions from a state-funded program which paid a parent or spouse to provide services, to the Medicaid program, the person is forced to find a new, probably unfamiliar and possibly less reliable, provider from an agency. More and more people will be facing this transition as the State increases its reliance on Medicaid.

Workforce issues can also impact choice. For example, different payment rates offered by different programs can limit choice. A personal care attendant performing the identical service for three individuals receiving services from three different programs might be paid three different amounts. If offered a choice, that personal care attendant is likely to prefer to provide services under programs offering the highest pay. Other factors impact the availability and choice among direct care workers including low wages and the lack of benefits and inconsistent public policies. For more information regarding workforce issues, see the IMPROVING QUALITY AND AVAILABILITY OF DIRECT-CARE WORKERS report.

Limited Choice Over Where to Live. In many cases, the choice of where to live is limited by the way services are structured. For example, some agencies offer both residential services and the case management or other supportive services intended to assist an individual in exploring alternative, more integrated living arrangements. These agencies can be confronted by a conflict of interest if the need for keeping tenants influences their inclination to assist an individual in pursuing an alternative choice.

As a related issue, many supportive residential services link the supportive services to the setting. That is, a person with a certain level of need will be required to move from setting to setting as his or her level of need varies. This passage along a "conveyor belt" of transitional settings occurs whether or not the individual prefers to stay in a location or would benefit from continuity in a particular setting.

For more discussion of housing issues, see AFFORDABLE, APPROPRIATE, INTEGRATED HOUSING**.**

What We Have Learned. Experiences in Maine and in other states demonstrate the positive benefits of integrating services and offering choice and control.

In Maine, the Children's Cabinet has sponsored an Integrated Case Management pilot to test ways of integrating services for children receiving services through multiple programs or providers. In one of the pilot communities, an independent facilitator was hired to work with the family to identify the child's and the family's needs. For some children this pilot has been found to be successful, streamlining and coordinating duplicative and complicated service plans.[5]

For consumer direction, more and more states, including Maine, have explored ways of increasing choice and control for consumers. Many states offer consumer-driven services for people with developmental disabilities (*e.g.*, New Hampshire, Vermont, Michigan, Wisconsin, Minnesota, Washington). Many states also offer consumer-driven services to the elderly and adults with physical disabilities (*e.g.*, California, Colorado, Kansas, Michigan, Oregon).

Early evaluations of these programs show promising results. In Arkansas, consumers (frail elderly and adults with physical disabilities) can use a monthly cash allotment to hire family members, friends, or others to provide care, or to buy equipment or devices that will increase independence. An evaluation of this program shows that 100% of the enrollees are satisfied with their relationship with their hired worker. [6] Ninety-five percent of enrollees were pleased with the times of day they could get help. One-third of program enrollees used their allowance to buy or repair equipment for personal activities, communication or safety. One-fifth bought or repaired equipment for such things as meal preparation and housekeeping chores.

Since l980, Maine has offered consumer-directed personal assistance services for adults with disabilities through a state-funded program. In l986, this model was adopted by the state Medicaid agency. In addition, a voucher program for the elderly and adults with disabilities is

[5] Spence, R. (2000) *Maine Children's Cabinet: Integrated Case Management Initiative assessment report.* Edmund S. Muskie School of Public Service: Augusta, ME.
[6] Brown, R. and Foster. L. (2000) *Cash and counseling: Early experiences in Arkansas.* Mathematica Policy Research Inc.: Manchester, ME.

administered by Elder Independence of Maine (EIM) and funded on an ongoing basis under the State's home-based care program. In this model, direct reimbursement is paid to the consumer for personal care attendant services. Presently more than 100 individuals take part in this very successful voucher program. Surveys of persons enrolled in this voucher program[7] revealed very high satisfaction with the program (93%), the range of choice, quality of help and other features. The survey also revealed that consumers need to be able to purchase employment support services for tax withholding, payroll and other administrative functions. The focus groups also documented how strongly people prefer having control over hiring and firing their own personal assistants.

Recommendations

We recommend the State adopt several guiding principles to govern the delivery of services to persons with disabilities:

- Service delivery is designed to meet the individual's or the family's needs, not the provider's convenience. Individuals and families have a choice among a broad range of service options and are able to participate in designing services and service delivery. Upon the choice of the individual or family, services are integrated and coordinated across programs, with a single comprehensive resource plan based on the full range of individual or family needs, not available services.
- To the maximum degree possible, individuals and families have the power to control and direct the services delivered, including the ability to recruit and select their own employees and deliver the paycheck.
- Individuals shall have access to case management or supportive services provided by individuals or an agency that are independent of the service provided.
- Standards for quality and accountability are built into the design of services and the State evaluates quality on an ongoing basis.

Integration of Services. We recommend that the design of services and the delivery of services be integrated.

We recommend that services be designed around individual needs and structured to maximize choice. For example, supportive housing services should be flexible so that a person can live where he or she prefers, and not have to move when his or her need for services changes. Instead, service levels need to adjust to meet changing need and, if need for services changes, the individual stays put (if that is his or her choice) and the services are increased or reduced as necessary.

For delivery of services, we recommend that some of the features of the Integrated Case Management pilot as well as other models reinforcing independence in service planning and delivery be made available in programs.

[7] Bratesman, S. and Richards, M. (2000, unpublished) *Preliminary findings from a survey of Maine's home-based care voucher program participants.* Edmund S. Muskie School of Public Service: Portland, ME.

Comprehensive Resource Plan. For each individual or family choosing to participate, we recommend that a comprehensive resource plan be developed. The resource plan considers not just resources provided by the State, but local private or community (*e.g.*, town officers or the church) resources, as well as family and friends. The resource plan is driven by the individual's or the family's needs, not by the services that are available. Inclusion of community and personal resources is critical to the success of the plan.

Independent Facilitator. We recommend that individuals or families have access to an independent facilitator or independent support worker or case manager to develop the comprehensive resource plan. In developing the resource plan, the facilitator or independent case manager or support worker works with the individual or family to identify strengths, needs and resources. It is critical that this individual be independent and not provide any other service except the facilitator or case management or community support service. By maintaining independence, the facilitator has no financial motivation to limit choices and service options and the independent case manager or support worker has no financial incentive to seek services from their own employer or disincentive to effectively monitor the services. In addition, the facilitator needs to have good facilitation skills and knowledge of the services available across different service systems as well as the different ways of thinking for different types of providers or disciplines. Facilitators, independent support workers, and case managers across the state should be trained so that they have a common structure for guiding the process. In this way, an individual moving from one region to another can move from one familiar process to another.

Brokerage of Service Delivery. For individuals or families choosing to participate in the facilitator model, we recommend that the facilitator supports the process of determining who will provide services to meet the individual's needs, by assisting the individual or family in identifying the people that could help meet those needs. Included should be individuals authorized by the individual or their family, possibly including case managers and providers, family members, and members of the community. Each participant identifies the resources that they can contribute. The facilitator should assist the group in identifying a lead case manager and assist in the transition for that individual.

For those individuals using a community support worker or case manager to develop a plan, services are thereafter developed with the support of this worker. In order to make this individual's role effectual, regulatory changes will need to occur that empower the client, in conjunction with a case manager, to engage and monitor services.

By reducing duplicative services, more providers will be available to reduce waiting lists.

The State's role is critical for this idea to work. We recommend that the departments within the State be at the table to address some of the systemic barriers to integrating services. By adopting the independent facilitator model, the State could develop a single coordinated process for integrating services through multiple entry points across all programs.

Choice and Direction of Services. We recommend the State expand consumer-direction across programs and populations, and types of services. In particular, we make recommendations regarding the development of a budget for consumer-directed services, the scope of services to be included in a consumer-directed budget, and new services that support self-direction.

Scope of services included in budget. We recommend that the entire range of long-term care and home and community-based services, including housing and transportation, be included in the individualized budget. That way, a person that might otherwise be required to live in a nursing facility could choose instead to purchase the in-home supports to make living at home possible. Or a person who needs transportation can decide the best way to meet that need. We recommend that the State move towards establishing a level of support based on the individual's health, functional status and living situation (including housing and transportation needs). In this way, individual choice and control is maximized.

The budget is determined based on the individual's level of need. The budget is the cash value of the services the person is eligible to receive. The individual can decide whether to use the money to purchase an allowable expense identified below, or to purchase training, or the services of an FEA (Fiscal/Employer Agent) or broker (see below).

In the short term, we recommend that the State increase funding for personal assistance services programs currently available, develop a mechanism to begin exploring the type of technology options referenced above, and study the possibility of standardizing eligibility criteria for personal assistance services across programs. In the long term, the State should develop strategies for expanding the budget to include a broader and broader base of services. The State should also explore options for using a range of technologies (*e.g.*, assistive, homesmart, telemedicine and durable medical equipment) and other supportive services, including service animals, which could reduce the number of hours that personal care attendant services would be necessary for an individual. These technologies not only improve functional independence but also allow support personnel to have more time to serve others.

Fiscal/Employer Agent (FEA). We recommend that the State develop an FEA (formerly referred to as independent service organization or ISO) as an optional service for persons directing their own care. This FEA could provide a range of services to the consumer and the consumer could decide to spend part of the direct funding budget on FEA services or save money by performing the services. The services offered might include a range of employee management services for employing attendant and other home services. The FEA could be responsible for withholding and filing employment taxes, preparing and disbursing payroll checks and processing employment-related documentation. The FEA could also train the consumer to perform these services, train the consumer to hire, fire, and supervise attendants, and provide other services to support the consumer in managing his or her services. The FEA could provide professional, technical, planning services to help people plan what services they need and how to get them. The FEA should use peers for skill training and consumer support.

Some individuals or families receiving services may not have the experience or sophistication necessary to make informed choices. Regardless of abilities and experiences,

the FEA is a supportive partner and helps the individual or family choose the necessary services. The FEA could employ service consultants to offer these services.

The FEA should not provide any of the services that the individual needs, other than services supporting self-direction. That is, while the FEA might aide an individual in selecting a care manager, the FEA does not provide care management services, or any other service that the individual or family might choose to purchase with self-directed dollars.

Surrogate decision making/eligibility criteria. The process of developing a comprehensive plan, with family members and others participating, should protect the safety of the persons being served. Eligibility for direct funding is not limited only to those people able and willing to manage their services. All people with disabilities should be given the option to direct their own care, either on their own, with the assistance of an FEA, or through surrogate decision makers. We recommend that the State set standards for who can and cannot be a surrogate decision maker. Some people are concerned that if the surrogate decision maker is a family member, the surrogate decision maker might have a conflict of interest that makes it hard to act in the interest of the consumer. At the same time, if direct funding is about flexibility and creatively meeting individual needs and preferences, family members are often in a better position to make those decisions. We recommend that family members be allowed to be surrogate decision makers. Vermont has recently implemented a consumer-directed waiver program for children with developmental disabilities up to the age of 21which could serve as a model. In the model, parents acting on behalf of their children determine the most appropriate services and people to deliver these services. We recommend Maine explore the options for both and adopt regulatory changes necessary to permit appropriate models. As discussed below, quality assurance standards will need to be established to ensure that all surrogate decision makers are acting in the interest of the person being served and that the integrity of each individual's self-directed goals are preserved.

Allowable expenses. We recommend that the State defines "allowable expenses" across departments with the input of consumers and other stakeholders, and includes them on a list of pre-approved services. Individual requests could be approved on an individual basis and collected for needs based utilization data. This could be a powerful proactive indicator of services to monitor for potential inclusion in the list of pre-approved services. Consumers working collaboratively with the State can establish criteria for evaluating when to approve nontraditional services. The criteria must be broad enough to stimulate flexibility and creativity, while focused enough to prevent the misuse of funds.

Quality and Accountability. We recommend that all services should have systems in place for assuring accountability and for quality.

We recommend that there be a "circle of accountability" in which all persons who are part of the comprehensive resource plan are accountable for their role in fulfilling the plan's components, including the individual or family member. When someone does fail to live up to an agreement, the reasons will be explored. For example, if a person fails to keep an appointment, the person needs to be asked whether a lack of adequate supports (*e.g.*, lack of transportation) was the cause. In some cases, an individual might not live up to an agreement about obtaining services.

A provider might fail in providing a service to meet an individual need or a community member might fail to provide a support that was promised. In these cases, when a team approach has been used, the resource team meets again to identify ways to implement the plan. Individuals using a community support or case manager model, would similarly meet to discuss remedies.

For consumer-directed services, some people are concerned that individuals or families might misuse direct funds. It is understood that fraud cannot be eliminated. We recommend that fraud be minimized by building in accountability and respect for consumer-directed services.

We recognize that the State needs to have some level of control over services purchased in a self-directed program. The State needs to articulate its expectations about fiscal accountability, and establish limits on financial vulnerability to risk for the individual or family.

We suggest adopting the following standards for individual accountability:

- active participation in planning and arranging for services and supports;
- register sources of satisfaction and dissatisfaction with services and supports;
- file grievances and complaints through proper avenues;
- learn and exercise rights and obligations as consumers;
- share relevant information;
- make informed choice;
- take advantage of opportunities to serve on policy boards; and
- complete information on progress toward outcomes and quality of service received.[8]

In the ADVOCACY, SELF-ADVOCACY AND QUALITY MONITORING report, we recommend that consumers play a role in defining and measuring quality. In addition we propose that the State develop quality indicators (with the participation of individuals and families receiving services) related to:

- the expected results of the services for the individual;
- how the design of the services meet the identified need;
- how the services will be delivered;
- the expected duration of specific services;
- possible alternatives for services; and
- how results will be evaluated.

The focus areas for setting these standards might include independent living, recreation and leisure services, employment services, housing, transportation, educational, and transitional services.

In addition, we believe that it is important to evaluate, on an ongoing basis, consumer satisfaction. The evaluation must be conducted by someone other than a provider or funder of services so that consumers would be comfortable being honest.

[8] *Vermont Self-Determination Project Summary.* Available: http://www.unh.edu/rwj/states/Vermont.html