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Consumer choice in home and
community-based long term care : policy
implications for decisionally
incapacitated consumers

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Ohio Long-Term Care Research Project

**CONSUMER CHOICE
IN HOME AND
COMMUNITY-BASED
LONG TERM CARE:
POLICY IMPLICATIONS
FOR DECISIONALLY
INCAPACITATED
CONSUMERS**

Marshall B. Kapp

November 2000



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**Consumer Choice In
Home and Community-Based Long Term Care:
Policy Implications For Decisionally
Incapacitated Consumers**

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November 2000

Abstract

In Ohio, as well as nationally and internationally, there is a strong movement to enhance the role of consumer choice, control, and direction regarding important aspects of publicly financed home and community-based long term care. The paradigm shift away from extensive government regulation of the who, what, where, when, and how details of long term care delivery and financing and toward greater consumer control over those matters, even when government is paying the bills, is premised on the existence of an autonomous consumer who is cognitively, emotionally, and physically able to act as an informed and voluntary decision maker. In many situations, though, the person who needs long term care is not capable of independently taking on the ideal role of autonomous consumer. This research project set out to examine policy-relevant issues pertaining to how choices about publicly financed home and community-based long term care are actually made, implemented, and monitored under a consumer direction model, but when the care recipient is unable to act as an autonomous, independent consumer selecting rationally among various home and community-based long term care options competing for the consumer's business in the marketplace. Specifically, this report: surveys publicly financed home and community-based long term care options now available in Ohio, with special emphasis on the consumer direction aspects of these programs; outlines the legal parameters theoretically applicable to informed consent and surrogate decision making in the consumer choice context; contrasts these legal requirements with empirical evidence about how consumer choices in fact are made, implemented, and monitored when the care recipient is personally cognitively and/or emotionally impaired; and presents related public policy recommendations.

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Introduction

Current efforts to enhance the role of consumer choice, control, and direction regarding important aspects of publicly financed home and community-based long term care (HCBLTC) represent a major international trend.

Current efforts to enhance the role of consumer choice, control, and direction regarding important aspects of publicly financed home and community-based long term care (HCBLTC) represent a major international trend (AARP Public Policy Institute, 1999; Merlis, 2000; Ono, 1999; Kapp, In Press). The United States is very much a part of this revolutionary shift away from traditional modes of extensive government command and control regulation (Kapp, 1996; Glickman, Stocker, & Caro, 1997; United States General Accounting Office, 1999; Stone, 2000).

A serviceable working definition of Consumer Direction is:

a philosophy and orientation to the delivery of home and community-based services whereby informed consumers make choices about the services they receive. They can assess their own needs, determine how and by whom these needs should be met, and

monitor the quality of services received. Consumer direction may exist in differing degrees and may span many types of services. It ranges from the individual independently making all decisions and managing services directly, to an individual using a representative to manage needed services. The unifying force in the range of consumer-directed and consumer choice models is that individuals have the primary authority to make choices that work best for them, regardless of the nature or extent of their disability or the source of payment for services. (National Institute on Consumer-Directed Long-Term Care Services, 1996, p. 4)

Justifications for consumer-directed long term care services include, among others (Kapp, 1999, pp. 28-35), individual empowerment, enhanced quality of life (Kosciulek, 1999), more flexibility and responsiveness to needs, and greater consumer satisfaction with services received (Benjamin, Matthias, & Franke, 2000; National Blue Ribbon Panel on Personal Assistance Services, 1999).

This report focuses on the consumer direction paradigm shift as it affects older persons. However, most of the issues identified and recommendations set forth in this report pertain with full force to disabled consumers of all ages, and a common agenda between the aging and disability communities has been recognized (Simon-Rusinowitz, Bochniak, Mahoney, & Hecht, 2000).

Several relatively recent developments have the potential to improve opportunities for older disabled consumers who presently rely on federal and state dollars to pay for their LTC services to obtain those services in the home or community rather than an institution. First, within the past several years the private sector has seriously undertaken a much larger role in the creation and marketing of LTC insurance products covering home care as well as institutional needs. To the extent that these private insurance products are successful in affordably supplementing or replacing traditional Medicare and/or Medicaid LTC coverage for a large part of the older and disabled populations, they will offer consumers valuable individual choice among insurance packages competing on the basis of coverage and price (National Association of Insurance Commissioners, 1996; Center for Long-Term Care Financing, 1998; Hayes, Boyd, & Hollman, 1999).

Second, each state—including Ohio—has obtained from the Secretary of the federal Department of Health and Human Services (DHHS) one or more waivers¹ that permit the state to use the federal component of Medicaid funds to match the state's contribution to pay for HCBLTC services that would not otherwise fit within the narrow coverage confines of the Medicaid statute and regulations (United States General Accounting Office, 1994; Leutz, 1999). A few states (e.g., New York under its Personal Care Assistant program) have found ways to offer a range of choices under their regular Medicaid plans. States also may fund HCBLTC services by appropriating their own dollars for that purpose (Kassner & Williams, 1997) and by obtaining federal funds under Title 3 of the Older Americans Act (OAA). The states may allow and encourage more consumer choice and control within waived or appropriated LTC services than strict Medicaid regulatory

mandates on consumers and providers would otherwise permit. In addition, private foundations are sponsoring several pertinent research and demonstration projects, including the Robert Wood Johnson Foundation's (RWJF's) Independent Choices and Cash and Counseling initiatives (Mahoney, Simon-Rusinowitz, Meiners, McKay, & Treat, 1998; Doty, 1998; Simon-Rusinowitz, Mahoney, Desmond, Shoop, Squillance, & Fay, 1997), which are intended to go beyond and build on the lessons of earlier experiences (Morris, Caro, & Hansan, 1998).

HCBLTC services funded by private insurance, Medicaid waivers, state appropriations, or private foundations may be provided under agency models. However, the recent developments noted hold the potential not only for helping to move more care of older persons out of nursing homes and into home and community-based venues, but also for enhancing the role of consumers in selecting and directing the details of that care.

The paradigm shift away from extensive government regulation of the who, what, where, when, and how details of LTC delivery and financing and toward greater consumer choice and control over those matters, even when government is ultimately paying the bills, is premised on the existence of an autonomous consumer who is cognitively, emotionally, and physically able to act as an informed and voluntary decision maker. In many situations, however, the person who needs LTC is not capable of independently taking on the ideal role of autonomous consumer. Under these circumstances, someone else must make decisions on behalf of the care recipient or assist that person in making decisions.

“A lurking question with all consumer direction is...how to handle the question of

agency for people of any age who are incapable of directing their own care” (Kane, Kane, & Ladd, 1998, p. 135). On one hand, there is a danger that persons with certain clinical diagnoses that, rightly or wrongly, ordinarily raise questions about decisional capacity will be discriminated against in the sense of health plans or LTC providers refusing to market or sell their products and services directly to them. Such reluctance would stem from fear that purchase contracts entered into may later be legally invalidated if challenged. Discrimination of this sort may violate the federal Americans With Disabilities Act (ADA)² and the Rehabilitation Act.³ On the other hand, a sense of nihilism toward, and neglect of, those who really lack the capacity to fend for themselves in a competitive marketplace must be avoided in a compassionate society that takes seriously its *parens patriae* (Kapp, 1995, pp. 51-52) obligation to safeguard the helpless.

Consumer direction in the context of HCBLTC entails a panoply of specific issues: whether to enroll in a particular program, what discrete services and how much of them to include in the service plan, who will deliver those services, and when and where they will be delivered.

Consumer direction in the context of HCBLTC entails a panoply of specific issues: whether to enroll in a particular program, what discrete services and how much of them to include in the service plan, who will deliver those services, and when and where they will be delivered. Negotiating this terrain may require the consumer to hone skills in, for example, hiring, paying, scheduling,

supervising, correcting problems with, and/or terminating one’s own home care worker(s). “[A] difficulty of this [consumer directed] option is that the complex care system makes knowledge and expertise necessary to translate the available money into the provision of care” (Hutten, 1996, p. 315). The acquisition of such knowledge and expertise, or the application of knowledge and expertise the consumer already has, requires at least a certain amount of mental capacity. An accurate appraisal of reality in this context lies, messily, somewhere in between the neatness of zealous consumer choice proponents who contend, on one side, that *everyone* is a fully independent, capable consumer (or who are content to quickly gloss over this concern) and the absolute position of firm opponents of consumer choice, on the other, who argue that *no one* except a government regulatory agency or its agent is sufficiently capable of handling the complex details of defining and managing a HCBLTC service plan. The research project reported here set out to examine policy-relevant issues pertaining to how choices about publicly-financed HCBLTC are actually made, implemented, and monitored under a consumer direction model, but when the care recipient is unable to act as an autonomous, independent consumer selecting rationally among various HCBLTC options competing for the consumer’s business in the open marketplace.

Following this Introduction, the report briefly surveys publicly-financed HCBLTC options presently available in Ohio, with special emphasis on the consumer direction aspects of these programs. Next, the report outlines the legal parameters theoretically applicable to informed consent and surrogate decision making in the consumer choice context. In the ensuing section, these legal requirements are contrasted with the empirical

evidence collected and analyzed in this project about how HCBLTC consumer choices in fact are made, implemented, and monitored when the care recipient is personally cognitively and/or emotionally impaired. This juxtaposition of theory and practice leads to the formulation and presentation of public policy recommendations.

HOME AND COMMUNITY-BASED LONG TERM CARE (HCBLTC) OPTIONS IN OHIO

As noted above, each state funds a variety of HCBLTC options—most of which traditionally have been agency-directed—using either Medicaid waiver dollars (Kassner, 2000), OAA Title 3 monies, or separate state appropriations earmarked for this purpose. The State of Ohio operates a number of HCBLTC programs; the most significant for older persons are:

1. Using funds made available under the **Older Americans Act, Title 3**, Ohio makes the following services, among others, available to older community dwelling citizens: home delivered meals, transportation, homemaker, adult day care, personal care, home maintenance, and chore. In 1999, the total cost of these services exceeded \$88 million (Ohio Department of Aging, 2000a, p. 4).

2. The Preadmission Screening System Providing Options and Resources Today (**PASSPORT**) program⁴ is a Medicaid waiver program which offers a variety of HCBLTC services to Medicaid-eligible community dwelling residents aged 60 and over who need a level of care comparable to that offered in a nursing home, in order to provide an alternative to nursing home admission for those individuals. Services offered include: adult day care, emergency response services,

home-delivered meals, homemaker, home medical equipment and supplies, nutritional consultation, personal care, respite care, social work counseling, transportation, nursing, and occupational, physical, and speech therapy. In 1999, total PASSPORT funding for all covered services exceeded \$127 million (Ohio Department of Aging, 2000a, p. 5), although this HCB component represents a very small percentage of the total Medicaid funds spent on LTC in Ohio. Most, but not all, PASSPORT administrative agencies around the state are housed within Area Agencies on Aging.

3. The **Ohio Home Care** program⁵ is a Medicaid waiver program that provides PASSPORT-type benefits for individuals who are younger than age 60 but otherwise would meet PASSPORT eligibility criteria.

There is evidence that Ohio's emphasis on HCBLTC is accomplishing its primary objective of allowing many older, disabled individuals to be cared for in their own home environments rather than in institutional settings (DeBrosse & Gulliver, 2000; Applebaum, Mehdizadeh, & Straker, 2000). This outcome is consistent with national trends (Liu, Manton, & Aragon, 2000; Barnes, 1995). In the 123rd Ohio General Assembly, H.B. 215 was introduced to create a Personal Assistance Services Program that would spend Medicaid dollars on HCBLTC for the disabled. Particularly in light of the United States Supreme Court's decision in *Olmstead v. L.C.*, 119 S. Ct. 2176 (1999), interpreting the Americans With Disabilities Act to disallow states from unnecessarily segregating public benefits-eligible disabled persons in institutions, this and other states' emphasis on developing and implementing HCBLTC options is highly likely, albeit not guaranteed (Appelbaum, 1999), to grow stronger during the foreseeable

future (Bazelon Center for Mental Health Law, 2000, pp. 12-13; National Association of Protection and Advocacy Systems, 2000). In the summer and fall, 2000, the Ohio Department of Aging (ODA) conducted an Ohio Access Forum in several parts of the state to solicit comments and recommendations from the public concerning the state's implementation of the Olmstead mandate (DeBrosse, 2000).

In addition to the HCBLTC programs administered by the state of Ohio, several programs are sponsored and operated at the local level in various parts of the state. Under Ohio Revised Code § 5705.71, "The electors of a county may initiate the question of a tax levy for support of senior citizens services or facilities..." Pursuant to this authority, voters in a majority of Ohio counties have established such dedicated levies; in Franklin, Hamilton, and Delaware counties, these levy funds are specifically targeted for in-home services to older persons (Benson, 2000). In Montgomery County, the ComCare program providing PASSPORT-type services to older individuals who need at least a protective level of care but not immediate nursing home placement (and who therefore are ineligible for PASSPORT) is one of many programs supported by a county Human Services Levy.

The various HCBLTC alternatives currently available in Ohio vary substantially in terms of the degree of consumer direction they embody.

The various HCBLTC alternatives currently available in Ohio vary substantially in terms of the degree of consumer direction they embody. Participants enrolled in the Consumer Options component of the Ohio

Home Care program⁶ have an option to hire, with Medicaid dollars, their own independent providers (the IP option) to provide them with specific services rather than receiving those services from home health agencies under contract with the Ohio Department of Jobs and Family Services. The PASSPORT program historically has embodied an agency, rather than a consumer direction, design. However, a task force (the CMY2K Group) of the ODA (the agency administering PASSPORT) in 2000 issued a set of policy recommendations revisiting that design. The CMY2K Group observed that, as it met, "The focus has gone toward consumer direction. It became more evident that PASSPORT's model needed to be revised from a one size fits all to an individualized approach." The Group's basic premises included:

- "Role of the case manager needs to be changed to emphasize consumer education in order to allow consumers to make informed decisions..."
- Practice should be consumer-directed to help consumers gain autonomy."

On the local level, the Council on Aging of Southwestern Ohio, working through a grant to the Scripps Gerontology Center, Miami University, is seeking to introduce consumer direction into Butler and Hamilton Counties' levy-funded Elderly Service Program (ESP) by allowing clients of ESP the option of selecting independent providers for the provision of their HCBLTC needs. An RWJF Independent Choices grant has been awarded to the Scripps Gerontology Center to work with the Central Ohio Area Agency on Aging, PSA 6, to conduct a demonstration project that will allow the use of Medicaid dollars to facilitate consumer directed HCBLTC for up to two hundred central Ohio

older persons who are already PASSPORT clients.

INFORMED CONSENT AND SURROGATE DECISION MAKING: THE APPLICABLE LEGAL REQUIREMENTS

In theory, legal requirements pertinent to the exercise of control in a consumer-directed model of HCBLTC are fairly straightforward. In order for choices about particular services to be legally valid, those choices must be made voluntarily, knowingly or intelligently, and competently. The informed consent doctrine is enforceable as a matter of Ohio's common law.⁷ It is also contained in standards of the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), including the standard requiring that patients be involved in choices relating to all aspects of their care (2000, Standard R.I.1.2). Although the JCAHO is a private rather than a governmental entity, and therefore compliance with its standards is voluntary rather than mandatory, the overwhelming majority of Ohio hospitals volunteer such compliance as a condition of JCAHO accreditation; since JCAHO is granted "deemed status" by the Medicare program for hospitals, accredited hospitals can avoid a mandatory annual survey by the federal Health Care Financing Administration (HCFA).

Moreover, the concept of autonomy or self-determination in modern American jurisprudence is a highly individualistic, isolated, and sequential one; that is, decisions to consent to or refuse particular health care or human service interventions may only be made at any specific point in time by *an* individual. If the consumer himself or herself is currently incapable of making a decision completely independently, *then a* single

surrogate to whom legal authority at that moment passes must make decisions on behalf of the consumer.

Technically, there are only two paths through which a surrogate may be formally legally authorized to act in the consumer's stead. One way to accomplish this transfer of power is by the consumer, while still capable of making such decisions, executing a durable power of attorney (DPOA) instrument empowering the surrogate-as-agent or attorney-in-fact to act on the consumer's behalf in the event of the consumer's subsequent incapacity. Ohio Revised Code § 1337.13 (A) (1) provides, "...subject to any specific limitations in the instrument, the attorney-in-fact may make health care decisions for the principal to the same extent as the principal could make those decisions for himself if he had the capacity to do so...in exercising this authority, the attorney in fact shall act consistently with the desires of the principal or, if the desires of the principal are unknown, shall act in the best interest of the principal."

When a consumer has failed to execute a DPOA instrument in a timely fashion and becomes so cognitively and/or emotionally impaired that he or she lacks capacity to independently make valid decisions, the only formal mechanism for authorizing a surrogate to act as decision maker is guardianship (referred to as conservatorship in some other jurisdictions) (Zimny & Grossberg, 1998). The guardianship process in Ohio, Ohio Revised Code § 2101.01 et. seq., entails a county Probate Court finding that a person (the ward) lacks sufficient capacity to make decisions and appointing another individual (the guardian) to make decisions for the ward. Unless explicitly limited by the court's order, a Guardian of the Person has the authority to make all decisions regarding an incompetent

ward's health care and other personal matters, including the array of issues involved in establishing, implementing, and monitoring the details of a comprehensive HCBLTC plan for a consumer.

Ohio Revised Code § 2133.08 authorizes a person's spouse, adult children, parents, adult siblings, and other relatives (in that stated order of priority) to make decisions about the withholding or withdrawal of life-sustaining medical treatment on behalf of a person who is incapable of making decisions but who has not executed a DPOA or been declared incompetent by a Probate Court. The limited scope of this surrogate decisionmaking authority conveyed by this statute (namely, life-sustaining medical treatment) makes it inapplicable to the HCBLTC context.

Ohio law concerning informed consent and surrogate decision making in the HCBLTC context is consistent with the status quo elsewhere. In New York, for example, the legislature in 1995 created a "Consumer Directed Personal Assistance Program."⁸ An **"eligible individual"** for this program, among other things, "has been determined by the social services district...as being in need of home care services or private duty nursing and **is able and willing or has a legal guardian able and willing to make informed choices, or has designated a relative or other adult who is able and willing to assist in making informed choices**, as to the type and quality of services, including but not limited to such services as nursing care, personal care, transportation and respite services." (emphasis added).

As the next section of this report explains, in actual practice regarding all degrees of consumer choice and direction in the HCBLTC sphere the relevant legal rules of informed consent and surrogate decision

making generally are honored much more in the breach than in the observance. Put differently, the legal authority of those who are really doing the "directing" in consumer-directed aspects of HCBLTC usually is quite murky at best. The policy implications of the prevalent gap between the law on the books and the practical process of consumer direction in HCBLTC are then discussed.

CONSUMER DIRECTED HCBLTC IN PRACTICE

Methods

In order to gain an understanding of the actual, as opposed to the theoretical, practice of decision making within the HCBLTC arena, the author/investigator engaged in qualitative research (Shortell, 1999). Specifically, during February, March, and April, 2000 the author interviewed forty-five key informants either in person or by telephone. All interviews were conducted individually and privately, with a promise of confidentiality, and lasted between thirty to sixty minutes. The composition of the interviewee group was: four national health policy experts, two representatives of national or state professional or trade associations, three state government officials, six directors of Ohio long term care regional ombudsman offices,⁹ nine executive directors or other staff members of Alzheimer's Association chapters in Ohio, twelve directors of PASSPORT agencies, five hospital discharge planners or Social Service department directors, and four individuals involved in consumer choice research and demonstration projects. The investigator took notes by hand during each interview and dictated and transcribed them afterwards. Since this research involved interviews with human subjects, the protocol was submitted to and approved by the Wright

State University Institutional Review Board (IRB).

During many of the interviews, specific relevant documentary materials were identified; these materials were obtained later and analyzed by the investigator. In addition, a thorough review of the legal, policy, health services, and gerontological literature was conducted.

Findings

Agency/Organization Involvement in Consumer Direction Issues

Interviewees represented a variety of agencies and organizations serving older persons. These entities may exert an important influence on whether and how consumer direction takes place. They become involved with these operational issues in a number of ways.

Consumers generally are referred to PASSPORT agencies by hospitals, home health agencies, various health and social service professionals, and families; self-referrals are relatively rare, but not non-existent. Some PASSPORT directors also reported that the regional LTC Ombudsman occasionally refers persons who have been admitted to nursing homes involuntarily (Kapp, 1998a) and who subsequently want to return home; in such cases, the PASSPORT agency frequently is able to arrange a suitable home care program for the individual. Additionally, it is not unknown for PASSPORT agencies to receive referrals from local Adult Protective Services (APS) agencies when the APS agency believes that the individual can be cared for appropriately in a home environment with services arranged through PASSPORT.

Most PASSPORT agency directors described their role as primarily providing information to consumers and their families about available service choices, assisting consumers and families to select among covered services and available service providers, and then supporting them in their choices. Directors stressed that it is especially important for them to explain the cost implications of different choices, so that the consumer can remain within financial limits allotted by the program, and indicated that most consumers are sufficiently able to comprehend this financial “reality check.” A few PASSPORT agencies, in addition to providing information, routinely engage as well in care plan development for the consumer. Other agencies report that, even when the consumer wants the agency to set up a care plan, the agency insists that the consumer or family make the key choices about particular services and providers.

Hospital discharge planners receive patient referrals mainly from physicians and other members of the health care team (nursing screens ordinarily are done on each admitted patient), as well as from family members. Discharge planners described a large part of their role as “reality testing” for patients and families regarding the kind of home care plan that can be devised within available resources. The prevailing philosophy appears to be that, if the patient and family cannot be disabused of their unrealistic expectations, “Sometimes you just have to send them home and let them fail.”

Alzheimer’s Association staff get involved chiefly in response to inquiries by the family members (more often adult children than a spouse) of Alzheimer’s Disease (AD) victims. In the absence of involved families, sometimes the local APS agency may request the Association’s input into its investigation¹⁰

about appropriate care for an individual. Almost invariably, families first ask the Association medical questions about AD (especially about the availability of any ongoing clinical drug trials in which the victim may be enrolled), and only later about LTC options. Alzheimer's Association chapters envision their role as that of educator, discussing various community resources and HCBLTC options, as well as the eventual likelihood of institutional placement. One staff member said her main function was to "provide lists"; through this informational exercise, as well as case management-like efforts to link families with selected services, the Associations enable families to make and implement more knowledgeable choices.

The general consensus of LTC Ombudsmen interviewed was that seventy-five percent of their calls from family members about finding LTC services ask for help in admitting an older person to a nursing home, but that a rising percentage of family callers are beginning to inquire about alternative arrangements, especially assisted living. Ombudsmen indicated that they receive few calls about home care possibilities; they surmise that families direct most of their questions in this area to hospital social workers, PASSPORT agencies, and home health agencies. Ombudsmen rarely receive service selection inquiries directly from consumers themselves, due to the depletion of mental and/or physical capacity that has occurred by the time that some sort of service selection is seriously contemplated. Since the primary role of the Ombudsmen is to investigate complaints about providers rather than to act as gatekeepers to the LTC system, most service selection inquiries result in the consumer being referred to PASSPORT for screening, although ombudsmen provide crucial information to families about the

quality of services available and how to make choices about them.

In many other circumstances, though, "consumer direction" is a misnomer for a process that might much more accurately be called "surrogate directed," or at least "jointly directed," HCBLTC.

Making Choices and Directing Care

Interviewees' responses to queries concerning how choices about (a) enrollment in particular HCBLTC plans, and (b) the details of specific services and providers within those plans actually are made indicate that the consumer direction paradigm can successfully serve to enhance the autonomy of potential and actual service recipients in many situations. In many other circumstances, though, "consumer direction" is a misnomer for a process that might much more accurately be called "surrogate directed," or at least "jointly directed," HCBLTC. Both in interviews conducted for this project and throughout the pertinent literature, it is routinely assumed by all key participants virtually without discussion or reflection that families will play *a*, if not *the*, dominant role in making decisions within "consumer directed" models. This automatic equation of consumer direction and family decisions is illustrated by the following description of California's Caregiver Resource Centers (CRCs): "The program operates on a *consumer-directed* care model. *Families* are given information, support, and skills to become *their own care managers*" (emphasis added) (Coleman, 2000, p. 7). The CRCs' client population is the family caregiver, even

though their program is labeled as *consumer-directed*.

In the RWJF Cash and Counseling demonstration, a non-self-directing consumer is eligible to participate if there is a representative (surrogate). One of the research goals of this project is to learn how the representative role works in practice.

Hospital discharge planners interviewed indicated that they routinely comply with JCAHO standards and look to the patient himself or herself as the decision maker regarding the discharge plan. When, however, the planner deems that the patient cannot be relied on to make necessary choices, that assessment is documented and surrogates are consulted. In the absence of a DPOA or a guardianship order, “available family members” are routinely turned to despite their lack of formal legal authority, and their choices are implemented.

PASSPORT is a voluntary program, and therefore requires consent for participation. A few PASSPORT agencies indicated that they have enrolled a number of clients with dementia. However, there was a strong prevailing view among interviewees that the vast majority of individuals enrolled in PASSPORT have adequate decisional capacity, at least at the time of initial enrollment, because the program chiefly serves persons who have physical rather than cognitive deficits. That orientation is probably related to the fact that Medicaid eligibility criteria for HCBLTC program waivers arguably discriminate against persons with dementia (O’Keeffe, 1999). Since persons with severe dementia are largely excluded from participation, questions regarding consumer incapacity appear to arise less often than might otherwise be expected in the PASSPORT context. There was a consensus

among interviewees that severely cognitively impaired individuals, particularly those who are impoverished and without highly involved family caregivers or others to assist on a daily basis, are more likely to live in nursing homes or assisted living facilities with special dementia units (Conklin, 2000) rather than in their own homes under a Medicaid waiver program.

PASSPORT agency directors agreed that, given that most PASSPORT enrollees have decisional capacity at the time of enrollment, both the decision to enroll at all and then specific choices about the service plan are ultimately made most of the time by the consumer, in consultation with the agency case manager. PASSPORT agencies generally have written policies guiding this process. In infrequent cases involving individuals who qualify for the PASSPORT program but who lack adequate decisional capacity to enroll themselves, agencies turn to obviously involved families (ordinarily adult children, and most often adult daughters)—with or without formal legal authority—for consent to enrollment and agreement with the details of a specific care plan.

The ability to defer or share important decisions offers a compromise that allows the consumer to be involved in care planning without being exclusively burdened with the array of details that autonomy regarding HCBLTC entails.

However, many consumers who have sufficient capacity to qualify as *the* decision maker choose to informally delegate decision making authority to, or more often to share

decision-making authority with, one or more family members. Some older persons, especially if debilitated by acute or chronic illness, intentionally choose not to direct their own care independently (Scala & Mayberry, 1997, pp. 11-12). The ability to defer or share important decisions offers a compromise that allows the consumer to be involved in care planning without being exclusively burdened with the array of details that autonomy regarding HCBLTC entails. Commenting about consumers who are somewhat cognitively impaired but who still retain sufficient capacity to function, from a legal perspective, as the decision maker, an RWJF Independent Choices project report noted:

Our findings on values and preferences suggest that, relative to other domains (e.g., environment/safety and social interactions), the primacy of personal autonomy may not be of critical importance to the person with cognitive impairment. Rather, the reciprocal nature of daily care decisions fosters interdependence and the concept of “delegated autonomy” (Collopy, 1988). This view of autonomy acknowledges a consumer-directed focus whereby the care receiver decides who they want to make and carry out activities in their place. (Feinberg, Whitlatch, & Tucke, 2000, p. 95)

“Families are involved and carry weight. They are equal partners in the discussion.” Family members, especially when they are functioning as caregivers, feel a “need to be at the center of the decision-making

process” (Martin, Hedges, & Johnson, 2000, p. 7). Indeed, when family members are functioning in essential caregiving roles, it is difficult to imagine them *not* being integrally involved in the decision making (Cohen, Yuskas, & Conroy, 2000). However, one PASSPORT director noted that he frequently encounters “more family involvement than we would like to see.” The dynamic of consumer deferral to, or collaboration with, the family (usually meaning the adult children) varies along a scale of activeness/passiveness depending on the particular consumer and family and their history of interpersonal relationships. It is not unusual for PASSPORT agency directors to feel themselves forced to accede to the family because “the client will not make decisions and we have to have answers from someone.” One regional LTC ombudsman suggested, in a largely critical tone, that service providers tend to defer to families even if the client has capacity, because families will make choices, pay the bills and fill out reimbursement forms, and overall be easier and more efficient to deal with than the older consumer.

The reality of informal authority delegation or shared, joint decision making in which the consumer is present but may be more or less actually in charge of decisions, although very common, is a model which the law—with its emphasis on individual, sequential autonomy discussed in the previous section—does not explicitly recognize.

The reality of *informal* authority delegation or shared, joint decision making in which the consumer is present but may be

more or less actually in charge of decisions, although very common, is a model which the law—with its emphasis on individual, sequential autonomy discussed in the previous section—does not explicitly recognize (Kapp, 1991). For example, consent forms developed for use in the PASSPORT program provide spaces for the signature of *either* the client *or* an authorized representative.

PASSPORT agency directors indicated that serious disagreements between consumers and their families rarely arise at the time of enrollment, but they may happen while the consumer is receiving services and declines to the point that the service plan must be reconsidered. Most such disagreements can be successfully “haggled out,” but when they cannot the majority (although not unanimous) observation was that the agency “has to go with the family,” both because family cooperation is seen as essential to the success of any home care plan and out of a misguided apprehension about the family initiating legal action against the agency.

Several PASSPORT interviewees noted that, on occasion, they notify the local APS agency when they believe an enrolled consumer, most frequently without an involved family, lacks capacity and is endangering himself or herself by refusing recommended services. The frequency of such notification varies substantially among PASSPORT agencies. It is noteworthy that decisions of a consumer with ambiguous capacity *consenting* to recommended services are accepted by coordinating agencies and service providers without question.

Despite their commitment to fostering consumer autonomy, several PASSPORT agency directors admitted that, when in a particular geographic area the availability of willing and able service providers (especially

personal care assistants) to care for PASSPORT clients is limited, the agency is more likely to be directive and less supportive of consumer wishes that call for a flexibility that the particular marketplace may not allow. Directors concede that, in such circumstances, it is more tempting for the agency to adopt an attitude of “Let’s go with whomever is willing and able,” than to focus on consumer choice. In the current robust national economy, a shortage of home care workers has been designated as “the top concern of the Ohio Department of Aging” (Ohio Department of Aging, 2000b; Even, Ghosal, & Kunkel, 1998). At the same time, PASSPORT agency directors noted that they must obtain at least consumer acquiescence with the details of a service plan, since a certain degree of consumer cooperation with providers is essential for the plan to succeed.

Yet, the conduct of any sort of formal assessment of consumer capacity, either when the client is initially screened for program eligibility or after the client has been enrolled in the program, is very much the exception rather than the rule.

Assessing Consumer Capacity to Direct Care

In examining how decisions are made about a consumer’s participation in a HCBLTC plan, the threshold inquiry ought to focus on assessing the cognitive and emotional capacity of the consumer, since informed decision making requires a competent decision maker—if not the consumer, then a surrogate. PASSPORT interviewees stated that they deviated from relying on the consumer (alone or in conjunction with the family) to make

decisions only in exceptional circumstances when the consumer was “clearly incapacitated.” Yet, the conduct of any sort of formal assessment of consumer capacity, either when the client is initially screened for program eligibility or after the client has been enrolled in the program, is very much the exception rather than the rule. Instead, assessment of consumer capacity seems in practice to be handled, usually unconsciously, mainly as a matter of clinical instinct or “feel”—an “I know it when I see it” approach.

For example, one PASSPORT agency director noted that, when a family requests an eligibility assessment and states that the individual to be assessed is unable to make personal decisions, the agency starts by accepting that statement at face value. This is based on the presumption that families act in their loved ones’ best interests. In many instances, interviewees observed, families can be either too precipitous, or too denying and reluctant, in accepting the consumer’s developing incapacity; whether a family asserts itself as surrogate decision maker prematurely or tardily often depends on prior family dynamics. When the family has not asserted decisionmaking incapacity on the consumer’s part, the PASSPORT assessors usually look only for “a minimum level of responsiveness and awareness of surroundings”; if the individual can express wishes, the agency ordinarily accepts those wishes at face value.

Another director indicated that her agency, in order to be flexible in tolerating sub-optimal consumer choices, often enters into behavioral agreements or “Acknowledgment of Risk/Negotiated Risk” contracts, but only for consumers “with *clear* ability to understand.” If her agency deems a consumer incapable of entering into such an agreement, that consumer “is an APS case.”

According to one LTC ombudsman, “There are times you can just tell” that a person is unable to make decisions personally, even if one’s criterion for sufficient capacity is only, “He seems to understand the problem and what he wants.” In the words of another interviewee, “You worry when the person lacks insight that he has a problem.” Others described as their working rules of thumb that capacity is questioned only when a person is “obviously delusional or disoriented” or “cannot follow commands.”

There was virtually universal agreement among interviewees that agencies and individual professionals responsible for managing and/or directly providing services in HCBLTC programs currently have poor measures of decisional capacity at their disposal, and that more precise tools and protocols are needed if more formal capacity assessment is to become a regular part of the process of screening potential consumers for eligibility for publicly-funded HCBLTC options.

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screens used by PASSPORT agencies, for example, do not specifically address the decisional capacity component. To the extent that this component is considered at all in the standard intake process, the consideration was described by many interviewees as “subjective” and “haphazard.” The consumer’s primary physician must certify that the consumer needs the appropriate level of services to be PASSPORT eligible, but that certification does not address the issue of decisional capacity. The Outcome and Assessment Information Set (OASIS) instrument¹ developed by HCFA to enable the systematic measurement of home health patient care outcomes contains a few questions relating to cognitive functioning, confusion, anxiety, and depression, but nothing specifically regarding the care recipient’s decisional capacity or need for a surrogate decision maker.

Existing capacity assessment instruments lack sufficient sensitivity and specificity to be very useful in this context (Kapp & Mossman, 1996). For instance, one RWJF Independent Choices project employed the commonly used Mini-Mental State Exam (MMSE) (Folstein, Folstein, & McHugh, 1975) to screen individuals, requiring a minimum numerical score for enrollment; the project report reflected afterwards that “We have no way to determine how many of the care receivers who were initially screened out because of scores below 16 would have been capable of participating in the research [on consumer direction].” (Feinberg, Whitlatch, & Tucke, 2000, p. 94).

¹ The current version of OASIS is available at www.hcfa.gov/medicare/hsqb/oasis.

Overwhelmingly, persons interviewed indicated that coordinators and providers of HCBLTC services generally take an informal approach to the issue of surrogates’ legal authority, preferring a “go with the flow” process that results in decisions getting made and implemented as efficiently and effectively as possible, rather than insisting that the surrogate be formally empowered through a DPOA or guardianship order.

Who Cares About the Legal Authority of Surrogates?

Overwhelmingly, persons interviewed indicated that coordinators and providers of HCBLTC services generally take an informal approach to the issue of surrogates’ legal authority, preferring a “go with the flow” process that results in decisions getting made and implemented as efficiently and effectively as possible, rather than insisting that the surrogate be formally empowered through a DPOA or guardianship order. Agencies routinely check to determine if such formal authority exists and are glad in the minority of cases when it does, since the identification of unambiguous decision-making authority creates an extra “comfort zone” for the agencies. At least partly for this reason, agencies—especially the Alzheimer’s Association chapters--strongly encourage still capable consumers to obtain legal assistance to execute DPOAs appointing an agent and otherwise to plan ahead for future mental and legal incapacity; many referrals are made to local Legal Aid offices, a number of which

have special units devoted to counseling older persons. However, when formal legal authority does not exist (the more usual situation), and even when families decline to follow an agency's recommendation to obtain legal advice, the agencies rely on the family (meaning "any relative or friend we can find who can sign a piece of paper") and its self-assertion of being in charge anyway. As one interviewee expressed it, "When a family claims to have legal authority, we don't make them prove it."

There was broad concurrence that consumers falling "somewhere in the middle" of the capacity/incapacity continuum create the biggest challenge for coordinating or care management agencies, service providers, and advocacy organizations. Nonetheless, or perhaps because of this factor, decision making about HCBLTC under publicly funded programs is often a matter that must be finessed pragmatically on a case-by-case basis. The watchword seems to be in the nature of "go with what works under the circumstances."

An exception, when an agency might encourage a family to obtain formal guardianship, is the situation of an assertive but incompetent consumer who is putting himself or herself in personal danger by making very bad choices or refusing to make necessary choices. If the family balks at the guardianship suggestion, the agency may seek to involve the local APS agency to gain legal authority to provide services over the consumer's objection. Interviewees noted that guardianship and/or APS scenarios more often than not were precursors to institutional placement. Put differently, by the time a situation has deteriorated to the point that agencies believe that guardianship and/or APS intervention are needed, consumer choice models of HCBLTC probably are not realistic.

Besides acknowledging the pragmatic need to "get the job done," several interviewees offered insights to explain the willingness, in most cases, of agencies coordinating and providing HCBLTC services to act without insisting on unambiguous legal authority for the surrogates. One person suggested that anxieties about potential agency liability for intervening without clear legal authorization usually center on the performance of major medical procedures, and not on the sorts of non-medical services that primarily characterize HCBLTC. Another interviewee observed that most agencies are more likely to insist on a surrogate having clear legal authority to make financial decisions on behalf of the service recipient than to press the issue when "only" personal choices are at stake. An additional observation was that hospital discharge planners and Alzheimer's Association staff frequently know family members from previous encounters, and therefore have a reasonably informed impression about whether the family can be relied on to act in the consumer's best interests.

Family members, with or without formal legal authority, sometimes disagree among themselves about a care plan. Most coordinators and service providers are reluctant to proceed in the presence of such disagreement, even if one family member has formal legal authority. Internal family disagreements ordinarily are resolved successfully through conferences with the planning team; interviewees talked about using these conferences and other teaching activities as opportunities to "empower" families. In rare instances of serious, intractable intra-family disputes, the initiation of a guardianship petition to clarify legal authority may be deemed necessary. Numerous interviewees indicated that they generally found local volunteer guardianship

programs to be very helpful in those circumstances.

Criteria for Surrogate Decision Making

There was consensus among interviewees that decision-making surrogates almost always commence the caregiving journey by trying to honor the consumer's wish to avoid nursing home placement (Kapp, 1998b); in this sense, surrogates are guided by the principle of substituted judgment, or doing what the consumer would want done if the consumer were currently capable of making and expressing fully autonomous choices. Interviewees attributed the dedication of surrogates to keep their loved ones in home settings as long as possible—and, according to many interviewees, too long—largely to a sincere commitment to the consumer's previously expressed autonomous values, and noted with admiration the enormous personal sacrifices and burdens that many family caregivers endure in fulfilling that commitment (McGrew, 1995).

When it comes to working out the details of a HCBLTC plan, however, the consensus was that surrogates tend to use a best interests standard. Although some interviewees, especially LTC ombudsmen, try to stress the substituted judgment principle by continually asking the family what “Mom would want” under the circumstances, reliance on a best interests standard is usually a practical necessity when the consumer is not able to competently articulate wishes at the time that decisions need to be made. Few individuals who become LTC consumers have articulated clear preferences about the specific details of their HCBLTC in advance of the need for those services.

When surrogates engage in best interests decision making that is consumer

centered, their first priority is to hire in-home workers who they feel will be responsive and responsible to the consumer. According to a PASSPORT agency director, most families start out wanting workers with impressive educational and professional credentials, but retreat when they learn how rare and expensive such workers can be in the HCBLTC arena. According to this interviewee, “Families come to understand that compassion and understanding are often more important than formal credentials.”

According to many interviewees, families *qua* surrogate decision makers often consciously or subconsciously analyze the consumer's best interests through the lens of their (the family's) own needs as caregivers. Under this view, a surrogate's decision to care for the consumer in the home rather than to seek nursing home placement may be driven by several motivations. First is the family's feeling of guilt at not being able to do more for their relative (“the martyr complex”) and apprehension that those feelings would worsen if promises made to the consumer were violated. Second, a family's legitimate need to pay attention to its own burdens may be exacerbated by the tendency of most families to defer making hard choices until a crisis atmosphere develops that multiplies those burdens and makes some definitive action unavoidable any longer.

Third, it would be naive to dismiss families' potential economic motives. One manifestation of those motives is seen in some families keeping even a very debilitated consumer in the home setting so that the consumer can continue receiving (with the relatives then taking and spending as the consumer's representative payee)¹¹ monthly benefit checks from the federal government through the Social Security retirement (Title 2) or disability (Title 16) programs. Many

interviewees argued firmly that this situation is not undesirable, as long as the consumer receives good care in the home.

Interviewees reported that some families request a wide array of services, whether or not those services are really needed by the consumer, just because public funds are available. Most of the time, however, economic motivations work in the opposite direction, namely, families refuse to enroll an eligible consumer in the PASSPORT or other Medicaid waiver program, or they consent only to minimal services within a program, in order to prevent the state from later recovering the costs of those services from the consumer's estate. The fact that the state must seek such reimbursement for Medicaid covered services¹² presents important policy issues that are discussed below. Families' wishes to conserve their eventual inheritances ("to save the family farm" or "to save the family trailer") probably act as the most powerful influence on the decisions that they make for their relatives about HCBLTC.

Monitoring Surrogates as Decision Makers and Caregivers

Attention has been paid elsewhere to methods of oversight aimed at the formal, paid workers in consumer directed HCBLTC models (Geron, 2000). The current project looked instead at the challenge of assuring that family members in this context are behaving properly in carrying out their multiple functions.

The consensus of persons interviewed was that, to the extent that external monitoring of family activity within the publicly-funded HCBLTC context occurs, it blurs any distinction between family members' caregiver and decision-maker roles. The general attitude appears to be, "We don't

police families" and "Who are we to say who should be monitored?" Instead, "oversight is built into the process of caregiver support" by myriad parties. This approach appears to be consistent with that of the federal government as exemplified in the Department of Veterans Affairs' Aid and Attendance program (United States General Accounting Office, 1998).

To the extent that monitoring takes place in Ohio's HCBLTC programs, the guiding principle is consumer safety.

To the extent that monitoring takes place in Ohio's HCBLTC programs, the guiding principle is consumer safety. When, but only when, family decisions (or even more importantly in many cases, a family's unwillingness to make any decision) seriously and imminently threaten a consumer's life or health do agencies intervene. This intervention usually takes the form of reporting the situation to the local APS agency for investigation and, if warranted, intervention. PASSPORT caseworkers ordinarily are nurses or social workers, who are covered under Ohio's mandatory elder abuse reporting statute.¹³ One PASSPORT agency director asserted, "We are not afraid to make the [telephone] call," but this was not a universally shared sentiment. A number of interviewees indicated that, although families are initially upset when an agency notifies APS, often those families later understand that there were serious deficiencies in the consumer's care and are willing to cooperate to address those deficiencies. In other cases, though, an APS referral is the last straw for a family that can no longer effectively care for an increasingly disabled relative and leads rapidly to the consumer's removal from the

home and placement in a LTC institution. Many interviewees reluctantly believed this to be the best outcome when continued living in the home would unreasonably (in their subjective judgment) endanger the consumer.

Evaluations of the effectiveness of reporting suspected abuse, neglect, or exploitation to APS varied markedly among interviewees. Explanations for wide differences among counties in the vigor of APS reactions to such reports included differential funding (and, therefore, staffing) levels, divergent philosophies (Schimer & Anetzberger, 1999) about the APS's proper role in promoting consumer/family autonomy (i.e., a focus on rights) versus vigilantly protecting vulnerable persons from harm (i.e., a focus on outcomes), and the willingness of each county Probate Court to order service interventions over the objections of a consumer and/or family. At least one PASSPORT agency has developed a productive consultative relationship with its local APS agencies, under which PASSPORT staff are welcome to call APS to discuss particular issues without filing a formal report.

Short of conditions rising to the level of suspected abuse, neglect, or exploitation, interviewees indicated that their agencies try to deal with perceived family shortcomings through family/agency conferences, supplying information and education, and other more or less formal means of support and advice. Most of the time, this results in a tolerable resolution, especially when the consumer's primary physician who ordered the care plan discusses the situation frankly with the family. One PASSPORT agency director, in noting that "All we can do when the agency disagrees with the family is to counsel the family about the consequences of its decisions and then abide by the outcome," described his agency as "a dog with no teeth." To emphasize the

consequences of a family's decisions and its performance in caregiving, PASSPORT agencies now commonly require families to enter into written Negotiated Assumption of Risk Agreements, which function in essence as waivers of liability if anticipated risks materialize.

Disenrollment of a consumer from the PASSPORT program is restricted to situations of unsafety, not just disagreement or discomfort. There are several ways in which disenrollment may effectively occur, such as the program's refusal to reaccept a client after a hospitalization due to safety concerns or dismissal of a client by a home health agency concerned about its own potential liability for providing services in an unsafe environment. A number of PASSPORT agencies indicated that they often work in collaboration with their local APS agencies, and sometimes with their regional ombudsman and legal aid offices, to resolve situations of inadequate surrogate performance short of disenrolling a consumer.

One PASSPORT agency director stated that monitoring is just an integral part of good case management, which entails an advocacy and facilitating role. Case managers have regular consumer contact, including both telephone calls and in-person home visits. They also encourage paid service vendors to act as "PASSPORT's eyes and ears" and to notify the PASSPORT agency about problems observed in the home and/or to report such problems to APS directly. Among other things, the PASSPORT case manager is routinely notified of any consumer's hospitalization. PASSPORT agency directors acknowledged that built-in monitoring by PASSPORT agencies will be less prominent as progress is made in the implementation of the ODA's CMY2K Group recommendations to move PASSPORT from an agency-directed to a consumer-directed model.

In the RWJF Independent Choices project in PSA 6, the level of the case manager's oversight will be geared to the needs of the specific client, as determined by specific criteria. For instance, capable clients and families will not automatically be called every month or seen every other month, as would normally be required in the traditional PASSPORT program. Adjustments in the intensity of oversight will be made as needed.

Virtually all interviewees expressed a bias that the danger of real and potential abuse, neglect, and exploitation of HCBLTC consumers by service vendor agencies is likely to considerably exceed that posed by families acting as caregivers and/or decision makers. The solid consensus was that most families who undertake voluntary participation in HCBLTC, especially in models with elements of consumer direction, truly are committed to the consumer's welfare and are grateful for the opportunity. At the same time, it was noted that persons at greatest risk are those who are either receiving only unpaid family caregiving or are paying formal caregivers privately out-of-pocket. Regional ombudsmen can assist in the latter context if problems arise and are brought to an ombudsman's attention, but the only regular external monitoring takes place in publicly-funded programs. A few interviewees expressed a fear (albeit without citing any evidence to support that fear) that families may avoid seeking available publicly-funded assistance in caregiving because they fear the home situation will be reported to APS even if they are doing their best for the consumer.

Individuals With Neither Decision Making Capacity Nor Surrogates

As noted earlier, the general consensus among individuals interviewed for this project was that, for persons without sufficient ability to independently, autonomously direct their

own HCBLTC, no available, interested family or friends almost always translated into no chance to participate in consumer-directed models of care. This group was described as a "bad fit" for those models. There is no credible estimate of the number of people who fall into this category in Ohio, but there is a strong belief that most of them are candidates for nursing homes or assisted living special dementia units sooner rather than later. As one interviewee put it bluntly, "These folks are out of luck." A number of interviewees who work for agencies serving rural Ohio areas claimed that, in rural settings, there is a deep prevailing ethic of families "taking care of their own," and hence it is rare that no willing family surrogate can be located for an incapacitated person.

PASSPORT agency directors stated that, since they do not conduct independent outreach initiatives to discover potential program participants, they do not encounter many persons with neither decision making capacity nor involved family or friends. Someone, ordinarily a family member, friend, or professional (especially after a hospitalization) has to bring a person to the PASSPORT agency's attention. When a PASSPORT agency encounters a person without decision making capacity, family, or friends, and it believes that the individual is in danger at home by himself or herself, a referral to APS usually is initiated. After investigation, APS agencies often work closely with the local volunteer guardianship programs that have been developed in many parts of Ohio to initiate a guardianship petition so that protective services (often including institutional placement) may be provided. PASSPORT directors indicated that, when a previously competent consumer without family or friends becomes severely decisionally incapacitated while participating in the program, they will "go along" with the

consumer's wishes until an unsafe situation develops in the home, at which time an APS referral is made.

Policy Recommendations

The findings about how decisions are actually made, implemented, and monitored in publicly-funded HCBLTC programs in Ohio which incorporate varying degrees of consumer direction implicate an array of significant public policy issues. Key policy recommendations emerging from an analysis of comments offered by persons interviewed and from a review of the relevant literature are:

1. Efforts to encourage and facilitate **advance planning for decisional incapacity** (e.g., by executing DPOAs) among potential consumers of HCBLTC should be promoted (McGrew, 2000). There was a strong consensus that many of the problems now encountered when families and friends are confronted with the need to make crucial decisions in crisis mode with little or no guidance about the incapacitated consumer's own wishes could be avoided or greatly mitigated if timely legal advice were obtained more often and issues of legal authority were clarified prospectively by the potential consumer and/or family. The Ohio Code should be amended to empower competent adults to explicitly include in their DPOAs a delegation to the agent of the authority to make decisions about the principal's HCBLTC issues, not just decisions about life-sustaining medical interventions. It is such expanded, more inclusive advance directives—social as well as medical in scope--

that persons should be encouraged to complete in a timely manner.

2. Although efforts to encourage and facilitate advance planning for future decisional incapacity among potential consumers of HCBLTC ought to be promoted, there appears to be little support for modifying either the present law or practice to insist that, in the absence of such planning, family members or friends be required to obtain formal legal authority to act as decision makers for the incapacitated consumer. Instead, **current respect for the decisions of surrogates even in the absence of clear, formal legal authority should be continued.** In other words, there appears to be a consensus that, despite the technical legal ambiguity associated with informal delegations of authority and the prevalent practice of shared or joint decision making, legal guardianship is overwhelmingly anti-therapeutic (Winick, 1995) and should be initiated only rarely to clarify the matter of surrogate decisionmaking power. In general, agencies and service providers ought to be allowed and encouraged to rely on “well meaning” surrogates even absent formal legal authority—i.e., to continue the usual practice of pragmatically “bumbling through.” Several interviewees spoke about their ethos of “moral reliance” on the family.

3. **Remove bureaucratic constraints** that unduly limit flexibility to adapt programs and service plans to individual needs without providing meaningful quality assurance or protection benefits to the consumer. The recommendations of the ODA's CMY2K Group to move the PASSPORT program more in the direction of consumer control, so that “[a]s a case manager's time is freed up by reducing or eliminating unnecessary or repetitious paperwork and procedures, they will have more time to work with consumers who need more intense interaction” is a

positive development. PASSPORT agency directors indicated that they would like HCFA to relieve PASSPORT agencies of the current requirement that they contract with any service provider in their geographic area who agrees to provide services within PASSPORT payment rates. Removing that mandate and allowing particular PASSPORT agencies to limit the number of approved providers offered to consumers would actually enhance consumer choice, it is argued, by improving quality of care and limiting business to providers who really want and are able to provide the services for which they are being paid.

4. There need to be developed **better criteria for identifying which individuals are suitable candidates to participate in consumer-directed models of HCBLTC.** “[D]evelopment of consumer-choice models should be accompanied with careful monitoring and evaluation to identify the appropriate candidates for consumer control...” (Feldman, 1997, p. 177). The ODA CMY2K Group Recommendations are a step in the right direction. Under the guidelines contained in those Recommendations, a person is appropriate for “consumer managed” PASSPORT when:

- “Consumer expresses desire/motivation
- Consumer is able to manage, organize & plan other aspects of their (sic) life
- Consumer’s support system is reliable, capable and stable
- Consumer/caregiver communicates well
- Consumer understands and accepts their (sic) role as consumer manager”

The Recommendations set forth a separate set of guidelines identifying candidates for Supportive versus Intensive levels of professional case management and supervision by the PASSPORT agency.

Under the approach represented by the RWJ Cash and Counseling demonstration project and by the New York Consumer Directed Personal Assistance Program alluded to earlier, eligibility for consumer-directed services is conditioned on the existence of *either* a capable consumer *or* a willing, able representative/surrogate to make necessary choices. One goal of the RWJF project is to learn more about criteria for determining when a representative/surrogate is needed.

5. Once appropriate candidates for consumer-directed HCBLTC have been identified, **the process for enrolling an eligible consumer in the appropriate program must be made less cumbersome.** Many interviewees criticized the time and “hassle factors” entailed in the current application process as a large disincentive for consumers and their families to take advantage of existing options.

6. There needs to be more and better **information and education** about HCBLTC service options made available to consumers and surrogates in a timely and accessible fashion, “so that the Area Agency on Aging doesn’t have to begin the educational process anew with each client and family.” For example, the National Association for Home Care (NAHC) uses its website for this purpose. The Care Choice Ohio information/consultation program² administered by ODA to promote and assist planning for long term health care needs and

² Information about Care Choice Ohio may be obtained from Area Agencies on Aging or by calling ODA at 1-800-282-1206.

living arrangements (McGrew & Straker, 1997) drew praise from many interviewees. Information and education regarding various service providers competing for consumers' business must include usable data about quality as well as price, availability, and other factors; the Long Term Care Consumer Guide to be published by the ODA under authority of H.B. 403 is intended to address this need as it pertains to nursing homes. In Great Britain, a private charitable organization has recently been established "to empower and inform people facing the challenges and complexities of long term care and to help them to become aware of their rights and responsibilities" (Windsor, 2000).

Information and education aimed at a public audience should cover, among other things, legal issues such as guardianship and its alternatives and instruction about the pragmatic aspects of the consumer role (e.g., how to hire, supervise, and fire a personal assistant). Alzheimer's Association staff stressed the importance of timely educational intervention with early stage dementia patients in order to encourage and empower them to take part in care decisions while still able and to plan for future incapacity, especially since most persons tend to become more suspicious and less cooperative as dementia progresses.

7. Beyond the receipt of information and education about options, surrogates and caregivers need various kinds of **training and support** on a continuous basis to assist them in fulfilling their difficult roles. The nature of that training and support ought to be adjusted according to individual decision making and caregiving circumstances and capabilities, taking into account the multiple levels and models of consumer direction possible. Valuable lessons may be drawn from an RWJF Independent Choices demonstration project that established a "Supportive

Intermediary" program for surrogates under a program of Consumer-Directed Home Care for the Cognitively Impaired (Mayer, 2000; Cohen, Yuskauskas, & Conroy, 2000). We may also learn from the proven successes of several state-funded caregiver support programs created to sustain families in their caregiving role and to maximize family decision making among service options (Family Caregiver Alliance, 1999; Feinberg & Pilisuk, 1999). Ways to make better use of religious congregations and workplaces as sources of emotional and intellectual support should be considered. A number of well-established and tested support programs created for developmentally disabled persons and their families have successfully maximized meaningful, informed involvement in HCBLTC service plan decision making by cognitively impaired persons (Pennsylvania Association of Resources, 1999), and these support programs might serve as models for older populations. The developmental disabilities literature also is more advanced than the current gerontological literature regarding consumer empowerment and involvement (Herr & Weber, 1999).

8. One of the reasons that most consumers and surrogates function in an atmosphere of relative ignorance about HCBLTC alternatives is that the professionals, particularly the physicians, to whom they ordinarily turn for guidance are themselves often unfamiliar with LTC options other than nursing homes. Thus, there is a serious, extensive need for **continuous professional education** regarding these matters, including education about consumers' rights and how to work with both consumers and families within consumer directed models. Case managers must be educated about their new consultative function, which contrasts sharply with the traditional professional role of gatekeeper and check writer. Public agencies need to train

clinical staff and case managers about ethical and legal issues and how they are translated into program services, attitudes, and behaviors even when the value of such translation cannot be quantified on a program evaluator's instrument. Attorneys and judges should be educated about the quality of life issues implicated by consumer-direction. A goal of professional education efforts should be improving communication among the various professionals and agencies involved in the care of HCBLTC consumers.

9. Everyone interviewed for this project complained about a lack of adequate **resources** to permit true consumer choice and direction to blossom. Typical was the comment, "The real problem with choice is that there just aren't enough choices." Improving consumer-directed HCBLTC services is virtually universally seen as dependent on the availability of more resources, with "improvement" here defined as maximizing the amount of services, the type of services available (e.g., many interviewees pointed out that more affordable, accessible transportation might increase the use of adult day care, which in turn might enable more people to avoid institutionalization), and the number and qualifications of service providers vying for the consumer's business. Allowing consumers to hire Independent Providers, such as what will occur within PSA 6's RWJF Independent Choices project, will vastly expand the pool of potential service providers but resources must be available to pay them. Several interviewees noted that, unless sufficient financial resources are available under PASSPORT to hire round-the-clock caregivers, few severely demented persons will ever be able to participate in the program. Exploring the use of public funds for assisted living ought to be a high priority. Opportunities for more cost sharing should be explored; there is a common

sentiment that many people who do not have the financial wherewithal to shoulder the entire expense would nonetheless be willing to contribute within their financial means to their own or their relatives' LTC care.

Many interviewees also advocated for more resources for local volunteer guardianship programs and Probate Court indigent guardianship funds, to facilitate legal clarification of rights and responsibilities in situations which are inappropriate for informal surrogate decision-making arrangements. To avoid their overuse, volunteer and indigent guardianship programs should build in a stringent screening process that diverts people for whom less intrusive alternatives are available.

10. Facilitate real consumer choice by **amending the federal¹⁴ and state¹⁵ Medicaid estate recovery laws**. At the least, the state statute's arbitrary and capricious distinction drawn between persons older and younger than age fifty-five¹⁶ should be eliminated. As noted previously, families not infrequently decline to enroll an eligible relative in PASSPORT or limit the services received in order to avoid subsequent financial recovery by the state against the consumer's estate for Medicaid-related expenditures. Perhaps more significantly, many potential consumers themselves choose to forego PASSPORT benefits in order to preserve their estates for their heirs. According to data compiled by ODA, in Fiscal Year 1999, 776 applicants for PASSPORT withdrew their applications because of anxiety about future estate recovery liability, and another 24 individuals disenrolled for the same reason. The comparable figures for Fiscal Year 2000, through May 8, were 620 and 15, respectively. Individuals who are eligible for Medicaid waiver services but do not receive them "manage" as long and as best they are able

(O’Keefe, Long, Liu, & Kerr, 1999). Many persons interviewed noted a tragically ironic and unintended consequence of the current law on Medicaid estate recovery, namely, when an individual’s mental and/or physical health deteriorates so badly that the family is no longer able to care for the person at home, APS often is notified, the individual is placed in a nursing home as a Medicaid resident (since the value of the individual’s home is exempt from Medicaid eligibility calculations but only for the first six months of nursing home placement unless a spouse or disabled child lives in the home),¹⁷ and Medicaid estate recovery provisions will apply eventually anyway.

associated with this model should be able to select other options.

For many, though, consumer direction offers an array of potential benefits.

These benefits should be made available to as broad a spectrum of the population as possible. However, the potential participation of individuals with severe cognitive and/or emotional impairments in consumer-directed models of HCBLTC raises a host of legal, practical, and policy issues. This report has identified the most salient of those issues and outlined a policy agenda for addressing them.

Conclusion

In Ohio and elsewhere, systems of home and community-based long term care financing and delivery are in the midst of a paradigm shift away from bureaucratic regulation and centralized professional case management, in favor of more opportunities for consumer choice and direction. The new paradigm will not be desired by, or appropriate for, every LTC candidate; as NAHC has stated in its Legislative Blueprint (2000, pp. 92-93):

Consumers have the right to choose the model of care that best suits [their] needs. Individuals who are capable and choose to should be permitted to self-direct care. However, those who are unwilling or unable to assume the many responsibilities

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Endnotes

1. 42 United States Code § 13996n.
2. 42 United States Code §§ 12101-12213.
3. 29 United States Code § 794.
4. Ohio Revised Code §§ 173.40, 5101:3-31.
5. Ohio Revised Code § 5101:3-12.
6. Ohio Administrative Code § 5101:3-12-12.
7. Nickell v. Gonzalez, 17 Ohio St.3d 136, 477 N.E.2d 1145 (1985).
8. New York Social Services Code § 365-f.
9. Ohio Revised Code § 173.18.
10. Ohio Revised Code § 5101.
11. 20 Code of Federal Regulations §§ 404..2001-2065.
12. Ohio Revised Code § 5111.11.
13. Ohio Revised Code § 5101.61(A).
14. 42 United States Code § 1396p.
15. Ohio Revised Code § 5111.11.
16. Ohio Revised Code § 5111.11(B).
17. 42 Code of Federal Regulations § 435.845.