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PASSPORT assessment and services

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CASE STUDIES

Hillary

Hillary is 65 years-old and has post-polio syndrome, a condition that afflicts many adults who had polio as a child. She has very limited mobility and is confined to an electric wheelchair. She has both a tracheotomy for breathing and a feeding tube; both tubes require skilled nursing care and monitoring. A widow for thirteen years, Hillary lives alone; she has had the help of PASSPORT since 2002. She has also received short-term care in nursing homes, once for twenty-one days of rehabilitation. Through PASSPORT, Hillary receives twenty-five hours per week of personal care and homemaking. One of her three personal care workers comes daily, gets her out of bed, showered, and dressed. At night, the worker returns to help her undress and into bed. Hillary also receives one skilled nursing visit each week. While she still drives her custom van at times, she uses medical transportation to and from doctor's appointments as needed. While Hillary is losing fine motor skills and becoming less ambulatory, she remains very involved in life. A nurse most of her adult life, she maintains her nursing license and is her apartment complex's "unofficial nursing R.N." She also volunteers, counseling and educating children and adults who also have feeding tubes. She says, "If I can help someone, why not?"

Gina

Gina is 83 years-old and has been married for fifty years to her husband Al, age 84, who is her primary caregiver. They have two sons who are within a 40 minute drive away, but the sons are not able to provide much daily help. Gina has been on PASSPORT since 2005, when her husband heard about the program from a neighbor who was receiving services. Gina's stroke (five years ago) and diabetes is taking a toll on her small frame. She is non-ambulatory, and requires help to transfer from bed to toilet, or bed to chair, for example. Al is equally small and is physically tired. He says, "I'm not getting any younger." Workers come in the morning, Monday through Friday, to get Gina out of bed, showered, and dressed. However, Al takes care of getting his wife ready for bed and transfers her there by himself. He also does all of the care on the weekends. He has requested more help in the evenings and on weekends because of his own physical decline. He wants to accomplish this by reducing some of the morning care and shifting it to the evening. Gina's case manager is worried about Al's ability to continue doing all the transfers by himself. Help has been added at night, but due to a shortage of weekend service providers, there is still no help on the weekends for Al. Al wants to take care of his wife at home for as long as he possibly can. The case manager has broached the topic of nursing home placement, but Al wants to continue caring for his wife at home. The case manager stays in regular contact with Gina and Al, phoning every month and visiting them every other month. "Al takes good care of Gina, it's just getting harder for him." Al praises Gina's case manager, "She's a good case manager. She's very responsive. When I call at 6:30 in the morning, she's there." The case manager is helping Gina and Al anticipate and plan for the possibility of nursing home placement when Gina's care needs exceed the capacity of Al and the PASSPORT program to keep Gina at home.

BACKGROUND

This report is one of five components of the PASSPORT evaluation conducted by Scripps Gerontology Center researchers. PASSPORT, Ohio's home and community-based Medicaid waiver program, provides an alternative to nursing facility care for Medicaid eligible Ohioans 60 years and older who have disabilities. PASSPORT program participants have access to a wide range of services and accommodations that allows them to remain in the community. To qualify for PASSPORT services an individual must meet all of the eligibility criteria for Medicaid reimbursed nursing home care. PASSPORT offers a range of services through waiver service providers, including personal care (bathing, feeding, dressing/grooming, feeding, toileting), home-delivered meals, homemaking and meal preparation, chore services, assistive devices and home medical equipment, medical transportation, and adult day services (ADS). Hillary and Gina, above, are two of 26,000 individuals who were enrolled in the PASSPORT program on any given day in 2006.

The Ohio Department of Aging (ODA) has overall responsibility for the PASSPORT program. The twelve Ohio regional Area Agencies on Aging (AAA) and one private non-profit agency (Catholic Social Services of the Miami Valley) are responsible for all of the client-level program implementation functions, service provider recruitment and contracting, and quality assurance. These thirteen agencies are designated as PASSPORT Administrative Agencies (PAAs). Each PAA has a PASSPORT site director who administers the agency's PASSPORT program.

PAA assessors and case managers have the responsibility to ensure that PASSPORT participants' needs are appropriately matched with services from a network of provider agencies. This occurs in three separate tasks. First, a plan of care and services is developed from an in-

home, face-to-face assessment in collaboration with the client, family, and is conducted by a PAA assessor. Second, a PAA case manager (who may or may not be the same individual as the assessor) arranges for services to be delivered, and provides ongoing monitoring and support to assure that services are provided according to the plan. Third, assessment is on-going; the case manager assesses changes in the consumer's condition or circumstances and modifies the service plan accordingly.

How does an older adult become a PASSPORT consumer?

A prospective PASSPORT consumer (or her family member or other representative) contacts the PASSPORT Administrative Agency. A preliminary screening is conducted by telephone, to identify basic needs and basic eligibility information. If the individual appears to have care/service needs, an in-home assessment is scheduled. If the prospective consumer is in the hospital or other setting awaiting discharge, an assessment may be conducted there, but an assessment is not complete until an in-home assessment is included. An in-home assessment may also be scheduled to address an individual's long-term care information needs, through ODA's "Care Choice Ohio" (or "Taking Charge") assessment program. The in-home assessment is conducted by a registered nurse or licensed social worker.

A number of assessment outcomes are possible. The prospective consumer may start the process toward PASSPORT enrollment; or she may be referred to alternative home and community-based services such as Older Americans Act services; or she may be referred to residential/institutional care such as assisted living or nursing home care (or she may be recommended for one of the other waiver programs). These outcomes are based on assessed level of need, level of informal support, income eligibility requirements, and the preferences of the consumer. If the process toward PASSPORT enrollment is begun at the time of the

assessment, an initial service plan is negotiated. A statement from the consumer's physician is obtained to certify need for services. If the individual is already a Medicaid beneficiary, services are arranged, a case manager is assigned, and services are begun as soon as a PASSPORT slot is available. If the individual is not currently a Medicaid beneficiary, she must apply through the County Department of Job and Family Services (CDJFS).

How are PASSPORT services delivered and monitored?

An assessment-based service plan is negotiated with the PASSPORT consumer and his or her caregiver(s) as appropriate. The following services are available through PASSPORT: adult day service; chore service; home medical equipment and supplies; emergency response systems; home delivered meals; homemaker; independent living assistance; minor home modification; nutritional consultation; personal care; social work counseling; and transportation. Services are scheduled with PASSPORT contracted service providers such as home health agencies or home-delivered meal programs; assistive devices and equipment, such as an emergency response button, shower chair, or grab bars are ordered if needed. A case manager is responsible for ongoing assessment and implementation of the service plan; the number of required case manager-consumer contacts is prescribed by the consumer's level of case management (consumer managed, supportive, or intensive). In some PAAs, the assessor continues as case manager; in others, these functions are separated.

How do PASSPORT services end?

A consumer is disenrolled from PASSPORT when she dies or when she chooses to leave the program. In addition, a consumer can be disenrolled when she no longer meets income, health, or safety eligibility requirements; when her needs exceed the cost cap; or when her doctor fails to approve the care plan. Disenrollment is the responsibility of the case manager.

The purpose of our evaluation component was to determine the effectiveness of the PASSPORT assessment process in ensuring that PASSPORT consumers are supported in making informed choices about long-term care; and whether the service plans developed for enrolled PASSPORT consumers are based on the assessed needs of and the informed choices made by the consumer.

The evaluation questions we addressed are:

1. Does the consumer exercise informed choice in the assessment, service planning, and service delivery experience?
2. Does the assessment process capture and accurately document the individual's needs, strengths, and resources?
3. Do both the service plan and service implementation match the individual's assessed needs and strengths?

METHODOLOGY

We used a case study methodology to conduct an in-depth evaluation of the PASSPORT assessment and services experience of thirty individuals and their families. When nearly all case studies had been completed, we conducted a focus group of twelve PAA site directors or their designees. Case studies allow an in-depth, process-focused examination of the program's many facets, with a focus on the three core questions. Case studies "dig deep" into the PASSPORT experience and allow us to evaluate both process and outcomes in detail. These case studies also allowed for direct consumer involvement and voice in the evaluation project. Case studies should not be used to generalize to the entire PASSPORT population. That is, the experiences of thirty PASSPORT consumers cannot represent the experiences of all PASSPORT consumers. That said, case studies help us to identify common and unusual issues, patterns of challenges and

successes, and the dynamic experience of PASSPORT consumers, their families, and the professionals who serve them.¹

Sample

Consumers

Our sample included at least one case study from each of Ohio's thirteen PAAs. We conducted cases studies in three categories:

“Newcomers”: Ten individuals receiving initial assessment, with follow-up after services had begun; this sample included the consumer, the assessor, the caregiver (where applicable), and the case manager.

“Continuing”: Ten consumers enrolled in PASSPORT for one year or more; this sample included the consumer, the caregiver (where applicable), and the case manager.

“Disenrolled”: Ten case studies (nine living and one deceased) of consumers who had disenrolled from PASSPORT; this sample included the consumer (if living), the caregiver (where applicable), and the case manager; the caregiver was the primary study participant in the case of the deceased disenrollee. Of the living disenrolled sample, seven had entered nursing homes; two voluntarily disenrolled due to an improvement in condition.

These different vantage points provided a comprehensive approach to answering our core evaluation questions.²

Our consumer sample included 26 females and 4 males. The age range was 61 to 95. Twenty-three consumers were White, one was Asian, and six were Black. Seven of our twenty total Newcomers and Continuing consumers lived alone; three lived with a son; four lived with a daughter; five lived with a spouse; and one lived with two adult children and their children. Five

¹ As we discuss findings from the case studies, we use the words “several,” “some,” “a few,” and “most,” rather than numbers, to guard against turning numbers into percentages generalized to the PASSPORT population and services.

² As our evaluation unfolded and our understanding of the PASSPORT program developed, we employed “emergent design” and modified our proposed methodology to better address our research questions. In particular, we evenly distributed the cases across types (Newcomer, Continuing, and Disenrolled) and we decided to include case studies of continuing consumers who had been in the programs *at least* one year, rather than *at* one year. This allowed us to examine longer PASSPORT histories.

of the ten Disenrolled consumers lived alone at the time of disenrollment; four lived with family caregivers; one lived in an apartment attached to her daughter's home. Length of enrollment for Continuing consumers ranged from one to ten years; Disenrolled consumer enrollment ranged from two months to six years.

Case study sample recruitment

Although we could not expect to achieve a representative sample using thirty case studies, we actively recruited a broad range of consumers and consumer experiences using a purposive sampling strategy. We also sought a wide range of assessor and case manager experience and were careful to include a balance of nurses and social workers. At the same time, we employed strategies to prevent sample bias. We were particularly careful to limit the potential of PAAs to “hand pick” cases as they assisted us in the recruitment process. We selected the dates of our observations and recruited new assessments from those already scheduled that day. Disenrolled and Continuing consumers were recruited by making specific requests of the PAA, for example, by asking for a consumer with a spousal caregiver, a consumer living alone, or a non-white consumer, etc.³ As the evaluation progressed, we were increasingly selective about the “type” of consumer in our attempts to build as inclusive and diverse a sample as possible.

Focus group

Our sample also included twelve focus group participants of either PASSPORT site directors or their designees.

³ PAAs contacted prospective participants to seek permission for us to meet them face-to-face, at the time of the assessment in the case of Newcomers, and at the time of the potential interview in the case of the Disenrolled and Continuing consumers. We then conducted an informed consent process, inviting participation; three potential participants declined consent, and we used back-up contacts arranged by the PAA.

DATA GATHERING

Case studies

Case study data gathering included a combination of interviews, observation, and document review. Documents reviewed included the intake screening tool, the initial assessment, service plans, case management case notes, reassessments, disenrollment forms (where applicable), and miscellaneous documentation, such as incident reports, hospital discharge notes, and physicians' statements.

For the ten Newcomer case studies, we observed the in-home assessment, interviewed the assessor, and, after services had begun, the consumer (where possible), the caregiver (where applicable and possible), and the case manager.⁴ For the three Newcomers who did not enroll in PASSPORT, we conducted a follow-up interview within two months of the assessment.

Focus group

The two-and-a-half-hour focus group of PAA site directors or their designees was designed to explore agency policy, procedure, and practice questions that emerged from the case studies. We presented preliminary case study findings, sought clarification and feedback, and conducted a semi-structured group interview. Researchers conducting other components of the PASSPORT evaluation also participated with questions. The group was audio-taped to ensure accuracy.

Program documents

We used the following documents as references for program policy and procedures: 1) "Ohio's Elder Care Management Network," a case management matrix published by the Ohio Association of Area Agencies on Aging; 2) PAA Operational Manual developed by ODA; and 3) Ohio Department of Aging memoranda as requested from ODA.

⁴ The primary researcher is a social worker with long-term care assessment experience. She included clinical judgment in her evaluation of the "accuracy" of Newcomer assessments.

FINDINGS

As a public program, PASSPORT is *one component* of a larger system of care that allows individuals to remain in their homes and communities. PASSPORT services may be provided along with: local programs, such as adult protective services, the Alzheimer's Association, and family and behavioral health services; churches; organizational charities, such as the Red Cross and food banks; housing service coordinators; the good deeds and sometimes considerable support of friends and neighbors; and to a significant extent, the family caregivers who remain the backbone of the home and community-based care system. Although not all PASSPORT consumers have family caregivers, the majority do. Though important and often overlooked, PASSPORT consumers themselves continue to perform those activities of daily living of which they remain capable. The exercise of self care is a right and responsibility of the home and community-based care experience; self-care activities are thus a vital part of the larger system of care. In fact, when consumers come to the PASSPORT program, they may have relied for months or years on their own determination and resilience and on the help of family or other informal caregivers. At some point, however, these individuals, at risk of nursing home placement, need and seek additional help. PASSPORT, family caregivers, and the consumers themselves are the key components of a combined effort to keep care at home as long as appropriate and desired.

How is it that consumers come to the PAA at a certain point in their lives? First, some come to the program after a health crisis, such as a stroke, or an injury from a fall. Others have experienced declines (sometimes precipitous) related to progressive illness, such as Alzheimer's disease or Parkinson's disease. Some consumers come to the program due to a caregiver crisis, that is, a sudden change in the caregiver's capacity to provide care. Or, the caregiver may have experienced gradual declines in capacity to care; this is especially possible with aging spousal

caregivers. The variability reflected in our cases studies suggests that the timing of inquiry and entry into the program is not easily predicted. Two of our evaluation participants did not, in fact, qualify for PASSPORT services at the time of assessment because they functioned too well to meet level of care eligibility criteria. The others, who did qualify, had varying levels of impairment and social support; no pattern explained the timing of their entry. Some were significantly impaired, had been for a long time, and required a high level of services; others were impaired enough to qualify for the program (ipso facto, to qualify for nursing home care through Medicaid reimbursement) and could do well with minimal services.

Informed choice

Does the consumer exercise informed choice in the assessment, service planning, and service delivery experience?

Long-term care decisions are among the most important decisions we make in a lifetime. These decisions affect where and with whom we live; how we will spend financial resources, both personal and public; who will enter our homes; who will be entrusted with our medicines, meals, and hygiene; even who will see and touch our naked bodies. Our decisions keep us safe and healthy, or they put us at risk. Long-term care decisions affect the nature of our social relationships and the activity and quality of our day-to-day lives. For many, the long-term care experience is one of the last experiences we will have with our families and friends. It very possibly may be one of the last important decisions we make alone or with the help of family members. In that sense, it is the way we leave this world. One cannot, therefore, overstate the value and importance of being fully informed about our long-term care options. We examine the issue of informed choice first by broadly identifying the issues and implications of the total PASSPORT experience. We then look at informed choice at the assessment, eligibility determination, service planning, and service implementation levels.

Threats to informed choice

Consumers make decisions about care in a step-wise process; there are multiple decision points where the exercise of informed choice is at issue. In the absence of a referral, consumers (and their caregivers) first decide whether to inquire about outside help. (What information and assistance sources are available to me?) This first step represents a giant leap in moving the consumer into the formal long-term care system, so the “point of entry,” that is, where one gets her information, is not insignificant. If the PAA is the point of entry for information about care options, the PAA is likely to conduct a preliminary intake screening to determine the need for and interest in an in-home assessment. From the list of options provided to them, consumers may decide to participate in the screening process, then an assessment. At the assessment they decide to ask for further information, to give or withhold their own information, whether to agree to the process toward enrollment, to agree to eligibility (liability; estate recovery; rights and responsibilities) and to the proposed level and types of services (a service plan), and choose which among a list of providers will deliver their services. Once services begin, the consumer decides how and when to communicate with the case manager, and how and when to assert preferences for change in the service plan, the provider(s), and the worker(s). Finally, the decision to remain a PASSPORT consumer is an ongoing one; the nursing home and other options remain before the consumer.

Our case studies revealed several threats to the exercise of informed choice, some inherent in the very vulnerabilities that bring consumers to PASSPORT in the first place. First, the consumer does not make decisions in isolation. Choice is negotiated with any combination of the following stakeholders: the consumer, caregiver(s), assessor, case manager, screener, service scheduler, service provider(s), direct care worker(s), and the County Department of Job and Family Services (CDJFS) Medicaid-eligibility worker.

Second, the consumer chooses among options identified and offered by others; others establish the range of choice, others delimit choice; others use language that is understandable or not to the consumer and her caregiver(s). Some consumers and their caregivers are referred to long-term care services, for example, by a physician's office or a hospital discharge planner. In these cases, information is given to the consumer about the options that are available; informed choice is therefore subject to the biases and motivations of the referral source. Is the prospective consumer given the full range of options? Is home care emphasized more than nursing home care? Or vice versa?

Third, PASSPORT and other long-term care information itself is complex and voluminous. The consumer and family have much information to "take in." And, consumers may be operating from a set of misconceptions, for example, about Medicare and Medicaid, requiring a "re-education" of sorts.

Fourth, the consumer (and informal caregivers) are often limited in their capacity to negotiate options on equal footing with program professionals and workers. The capacity to understand options and decide among them may be limited by cognitive impairment, sensory or language impairments, low literacy, a lack of general information on the topic, and language and cultural barriers. And, the lack of energy that many individuals with chronic illnesses and impairments experience may significantly interfere with their ability to absorb information and to express and assert personal preferences. Finally, the negotiation of options may be conflictual, for example, when the consumer and her informal caregiver have competing preferences.

Professional discretion and consumer choice

At the program level, assuring informed choice among vulnerable consumers requires ongoing commitment, vigilance, and the application of empowering practice strategies at each

decision point in the consumer's PASSPORT experience. A major finding in this report is the significance of the role of professional discretion and judgment in the PASSPORT experience. Discretion is the decision making freedom left to the professional after all policies, rules, and regulations have been applied. The decisions made by PASSPORT professionals related to sharing and explaining information have a significant impact on the consumer's informed choice. Although PASSPORT assessors and case managers do follow policies, rules, and regulations to provide required information to consumers, as professionals they have leeway about how much information to add, how to explain the range of options as they might be applied to the consumer, and how much of their own biases and perspectives to offer. These decisions require the use of professional judgment. We will explore other consumer and professional issues related to informed choice in our examination of assessment, service planning, and service implementation in the PASSPORT program.

Assessment

Does the assessment process capture and accurately document the individual's needs, strengths, and resources?

According to the PAA Operational Manual, assessment “means the process of evaluating the individual/consumer's functional and cognitive capacity and limitations, needs, strengths, abilities, and resources” (Section 1: Overview and Definitions, p. 3 of 7). We maintain that an effective assessment is **shared** (uses multiple sources of input), **ongoing** (reflects changes over time), and **developmental** (builds upon itself to broaden and deepen knowledge over time). All three elements of effective assessment were found in our evaluation of the PASSPORT program. In fact, the ongoing aspect of assessment is an explicit ODA expectation. “[T]he assessment process is ongoing to ensure continual awareness and updating of the individual's situation so

that needs may be met in the most appropriate manner” (Section Two: Assessment. PAA Operational Manual, p. 1 of 3).

As a shared process, the assessor incorporates her own observations and perspectives with information and perspectives from the initial intake screen, the consumer, the caregiver(s), the physician, and where applicable, the discharge planner from a hospital or other institutional setting. As an *ongoing* process, assessment in the PASSPORT program begins with the initial in-home assessment and is modified by case managers in ongoing contacts with the consumer, caregiver(s), service providers, and others. This ongoing process includes in-home reassessments at least annually.

Initial assessments

Of the ten observed initial assessments, seven resulted in PASSPORT enrollment. Of the three not enrolled, two did not meet the level of care requirement. The husband of the third prospective consumer declined services on behalf of his wife, who has dementia; he expressed a desire to continue to provide his wife’s care on his own, “as long as [he is] able.” He sought the assessment to become informed about future options; the assessor used the assessment as an opportunity to “get [her] foot in the door” with a prospective consumer who clearly qualified for services. In each of these three cases, the assessor treated the process as an opportunity to educate the consumer and family about programs, benefits, and future long-term care options.

In all the observed initial assessments and in the review of initial assessment documents from the other case studies, the assessment process appears to effectively capture and accurately document the individuals’ needs and strengths, sufficient to develop and begin an appropriate service plan. We did observe several challenges in the assessment process and offer recommendations accordingly.

It is helpful to begin with a look at the assessment experience from the consumer's perspective. What does the initial assessment process ask of the consumer and his or her caregiver(s)? However necessary, the PASSPORT assessment represents an intrusion by a stranger into the home and life of the consumer and caregiver(s). Individuals are asked about very personal matters, such as elimination habits, mental health, family relationships, and medical history. The individual may be asked to demonstrate some of his or her activities of daily living (ADLs) and instrumental activities of daily living (IADLs), functional capacities such as range of motion in arms or legs, including ability to tie shoes or put on socks, or reach to comb or wash one's hair. The assessor takes a tour of the home to evaluate the safety, accessibility, and suitability of the environment. This requires a look at the bathroom and bedroom, generally considered the most private of home spaces. The individual may be asked to demonstrate mobility and dexterity in getting in and out of the bathtub or shower, or using kitchen appliances. Individuals must supply all financial documents needed to evaluate income and assets for a preliminary financial eligibility determination. Finally, the assessment takes approximately an hour and one-half to two hours to conduct. Not only has the consumer *provided* a lot of information, she has *received* program information, verbally and in several sets of documents full of new jargon. In most cases, the assessment concludes with negotiations for next steps, either referrals or a PASSPORT service plan, or both. The assessment can be fatiguing and overwhelming to consumers and families, and as program evaluators, we observed those effects, even where assessors exercised model efficiency and sensitivity. We also observed expressions of relief and gratitude from the individual/ family for the time spent and the services offered.

The initial assessment has two basic functions: to gather information from the consumer and to educate the consumer about the PASSPORT program. What does the assessor expect to learn from and provide to the individual in a two-hour assessment? From our observations, our assessor interviews, and the focus group, we conclude that an initial assessment is considered successful *if*: a) enough information is gathered to assign a level of care for eligibility purposes and to develop, on the spot, a *preliminary* plan of action to meet the immediate needs of the consumer (either an initial PASSPORT service plan or a referral to another source of care and services); and b) sufficient information is provided to the consumer to help negotiate a more permanent plan of action.

It seems clear that assessments lasting longer than two hours would exceed the patience and capacity of most consumers and their caregivers; longer assessments would also tax the PAA's human resources. Yet the assessment instrument is twenty-two pages long and extremely detailed; if every field in the instrument were filled in the first assessment, the process would take considerably longer than two hours. None of the assessors in the observed initial assessments completed every field in the assessment instrument. The fields for ADL and IADL measures were consistently filled in, such as bathing, mobility, and meal preparation. Less consistently filled in were systems review areas such as mouth/throat and genitourinary/gynecological systems. Such areas *were* recorded if they emerged as important to the understanding of the consumer's function or to a fragile state of health.

Efficiently using time to gather and share information is not the only limitation or challenge faced by the assessor. The consumer characteristics that sometimes impede informed choice, identified earlier, also present challenges to the assessor. These include cognitive impairment, sensory or language impairments, low literacy, language and cultural barriers, and

low energy. In addition, the amount and complexity of PASSPORT information to be communicated to the consumer and caregiver(s) presents a significant challenge.

Finally the practice of shared assessment, that is, using input from multiple sources, is both an asset and a challenge in the assessment process. Clearly multiple sources enrich the understanding of the consumer's care needs and capacities, but these multiple sources may present different, even conflicting perspectives. In particular, we observed consumers asserting their abilities to perform certain ADLs, and caregivers reporting these ADLs as impaired. This sometimes happened in what we might call the "back-porch" assessment, when the caregiver caught the assessor upon leaving to "correct" or "clarify" the consumer's self-report, out of consumer earshot. The assessor's observation of the consumer's functional capacities is especially important in these cases. Shared assessment also takes extra time, and time efficiency is an obvious challenge to the assessors. The assessors we observed demonstrated patience and openness with all the principal actors involved in the assessment.

Our evaluation finds that assessors do appear to gather enough data to confirm the eleven program eligibility requirements, to evaluate ADL and IADL needs, the availability of informal caregivers, and to achieve the best fit in an initial PASSPORT service plan (or appropriate referral). Assessors exercised professional judgment and discretion about which fields to complete while sitting in the home of the consumer before negotiating a plan of action, and which fields to allow to remain unfilled when handing off the case to the case manager for ongoing monitoring and assessment. The operating expectation is that more will be gathered and more will be learned through ongoing contact with the consumer.

Although the PASSPORT assessment is intrusive and can be overwhelming, the process is essential to determining eligibility and achieving an appropriate service outcome. Conducting

the assessment in-home is mandatory and should remain so. Observation is a central assessment tool and the assessor can evaluate the home's appropriateness as a care setting and as a workplace for in-home service providers. The assessor observes ADL and IADL capacity rather than relying solely on the consumer's self report. The assessor also observes the interaction between the caregiver(s) and the consumer, part of the evaluation of informal support.

Our evaluation finds little difference in the assessments conducted by nurses and social workers. All assessors appeared skilled at conducting all areas of the assessment. We did note in the observed assessments that the nurses spent more time scrutinizing the medications of the consumers than did the social workers. And, in one case, a nurse assessor reported that she did not have the skills to get into a sensitive issue that arose during the assessment (related to the consumer driving a vehicle). This assessor asserted that a social work assessor might have felt "more comfortable getting into that." There was also no notable difference between nurse and social work case managers in the case management process and outcomes.

Caregiver assessment

We were struck by the variability among assessors in the level of attention to caregiver assessment. Caregiver assessment is a recent addition to the assessment tool. Several assessors left this field blank in the assessment. Assessors did evaluate the availability and intended level of caregiver involvement, but many did not evaluate caregiver strengths and needs, including emotional needs. When we asked about this omission in our interviews, many pointed to time constraints as the reason. Assessors also believed that the relationship that caregivers would develop with the consumer's case manager would serve as a source of ongoing, developmental caregiver assessment. Indeed, we found this to be true in the case managers' case notes.

Initial assessment and informed choice

Earlier, we identified several threats to consumer informed choice. In our assessment observations, we noted efforts of assessors to ensure informed choice in the face of the threats identified above. As we have said, the two-hour initial assessment is designed to include time for educating the consumer about the PASSPORT program and eligibility policies. In cases where the consumer's decision-making capacity and assessment was impaired, the assessor communicated primarily with the caregiver, involving the consumer as appropriate. We never observed inappropriate involvement of the caregiver in the assessment and informed choice process. Importantly, the assessment tool does not explicitly address the individual's decision-making capacity and threats to informed choice; adding such a component would enhance the assessor's and case manager's ability to facilitate consumer informed choice.

The PASSPORT program and regulations are complex, they use a vocabulary that is often new to the consumer, and information is voluminous. Financial eligibility criteria and policies (such as Medicaid estate recovery) are particularly complicated and have very real potential consequences for consumer and family finances. Examples of PASSPORT vocabulary include "Medicaid waiver program," "level of care," "estate recovery," "enrollment/disenrollment." We observed variability in the assessors' use of unexplained jargon; in our follow-up interviews, we asked those few assessors who used more jargon about this practice. In each of these cases, the assessor talked about how "easy it is" to slip into jargon and abbreviations, and how she is always having to guard against this. In *all* observed assessments, assessors invited questions from consumers and caregivers at multiple points in the assessment.

Consumers and their caregivers were provided with approximately nineteen written documents or flyers at the time of the assessment. Most of these materials are essential to the informed choice objective of the enrollment process, such as the eleven PASSPORT eligibility

criteria, an explanation of Medicaid estate recovery, and the PASSPORT consumer's Bill of Rights and Responsibilities. A few, however, were less immediately necessary, such as the "Knock, Knock...Who's There?" theft prevention flyer. In all cases, assessors provided materials in a book or folder; each document or brochure was explained by the assessor as the assessment and enrollment process progressed. All consumers and their caregivers were told by the assessor to read the materials and call with questions; most sympathized with consumers that "this is a lot to take in," and expressed reassurance that the case manager would help them navigate the program and respond to questions as they arose. Indeed, case management case notes indicate that consumers and their caregivers become increasingly program-savvy over the time of their PASSPORT experience. One caregiver said, "[At first] I felt confused and overwhelmed but the assessor assured me it would work out....I think she is very wise and very thorough. And I have talked to [the case manager] quite often on the phone."

Thus far we have focused on informed choice issues related to the consumer's understanding of the PASSPORT program. We were also interested in whether consumers were informed about their full range of long-term care options, including nursing home placement. In most cases, the assessors began their introductions to PASSPORT by explaining PASSPORT as a substitute for nursing home care; some explicitly stated nursing home diversion or delay as the goal of the program. In no cases, however, did assessors "push" the PASSPORT program as the only option for consumers. None of the observed assessments resulted in a referral to nursing home placement. Yet, it is important to note that in some of the Continuing cases, case managers actively worked with consumers and their caregivers to keep the nursing home option open and always "on the table." And, of course, several of the Disenrolled consumers left the PASSPORT

program due to need for nursing home care, a process that was undertaken with the counsel and assistance of case managers.

Initial service plan and informed choice

Once the consumer has decided to preliminarily enroll in the PASSPORT program, she and his or her caregiver(s) negotiate an initial service plan with the assessor. This negotiation requires frank and sensitive communication among all parties. Most assessors have broadly explained the range of PASSPORT services at the beginning of the assessment. At the conclusion of the assessment, most assessors ask the consumer (and/or caregiver as appropriate) to identify what she needs (sometimes, as opposed to *wants*) in the way of help. In some cases, the assessor suggested an explicit “package” of services, for example, “How about one hour of homemaking, three days a week, and two hours of personal care, four days a week?” In other cases, the assessor allowed more initiative from the consumer in suggesting a service plan. In all cases, the assessors worked to balance the consumer and caregiver needs and wants with a relatively conservative offer of PASSPORT resources. One assessor described a “start low and go slow” approach to the initial service plan, explaining that it is easier to add services later than to remove them. We discussed this perspective in the focus group, where the consensus among participants was that, although it *is* easier to add services than to remove them, the ultimate objective at every step in service planning and delivery is the best fit between consumer need and services delivered: no more services than needed, but no fewer than needed, from the beginning to the end of the PASSPORT experience.

Assessors use discretion in the negotiation of the service plan. They decide how much to offer or suggest to the consumer. They sometimes offer perspectives about particular service arrangements, such time-of-day scheduling, the advantages and disadvantages of adult day

services, or the type of home-delivered meals, hot or frozen. They may even offer perspectives about the pros and cons of having one direct service worker, vs. multiple workers. Some consumers deferred to the suggestions of assessors more than others. Clearly the use of discretion requires strong assessment skills and good professional judgment, traits apparent in each of the assessors we observed.

In negotiating the service plan, the consumer and caregiver are given a list of providers, for example for home-delivered meals or personal care agencies⁵. Sometimes this list is very long. If the consumer states a preference, the assessor is required to arrange services from the preferred provider if available. If the consumer expresses no preference, the assessor, by policy, assigns an available provider from a referral list in order of lowest cost. We observed that consumers often chose providers according to name recognition, e.g., an emergency response system they had seen advertised on television; some other consumers chose providers that had been used successfully by friends or family.

The selection of a provider or providers is a significant informed choice issue for consumers, assessors and case managers. For a consumer, having a list of providers is not the same as being informed about them. According to policy, the PAA “shall develop a policy to facilitate consumer choice in the selection of PASSPORT service provider” (Section Four: Enrollment. PAA Operational Manual, p. 3 of 3). We found that assessors and case managers are frustrated by their inability to provide the consumer information about the quality of providers and thus to assure a quality service plan and to prevent quality-related disruption and discontinuity of services. Provider feedback logs, used by most PAAs, but apparently used inconsistently within PAAs, are not trusted to provide shareable, objective quality information.

⁵ During the period of our assessment observations, the rule requiring that the list of providers is to be shown to consumers was rescinded. We learned in the focus group that some PAAs continue this practice even though no longer required.

Even though assessors and case managers have a history of experiences with the providers and as such are a source of information, they are prohibited from providing that information to the consumer. One focus group participant said there is a shortage of “good providers” and argued that providers are often “more work... than the consumer is... I don’t know how we can weed them out or not take them in the first place... There are no quality measures in any of the provider lists out there.”

Once the service plan is underway, the consumer may seek a change in workers within a provider agency and may change the provider agency itself if an alternative is available. Several of the consumers in our case studies exercised these options.

Financial eligibility and time of onset of services

We examined whether PASSPORT consumers were enrolled in the program in a timely manner. Especially for consumers who come to the PAA at a point of crisis, a delay in service onset increases the risk of health declines in both consumer and caregiver, and hence the risk of nursing home placement. Two things can significantly delay the onset of PASSPORT services: 1) the process of Medicaid eligibility determination (made and renewed annually by the CDJFS) and 2) the PASSPORT waiting list. It appears that much of the waiting list time overlapped with CDJFS delays. On March 8, 2007, well after our data gathering, Ohio Governor Ted Strickland issued a directive calling for expansion of services to the 1,100 Ohioans on the PASSPORT waiting list.

Medicaid eligibility determination can be delayed by the consumer or by the CDJFS. It is incumbent upon the consumer (or her representative) to gather necessary financial documentation for a face-to-face appointment in the CDJFS office. One consumer’s caregiver described the process: “I had to gather a lot of information. I had lost the birth certificate, and I

had a list of twenty-five to thirty things I had to gather up. I went for the appointment and was only missing about six things. [The CDJFS worker] gave me a week, and my son and I found or replaced the missing things and my son finally ran them into the office.”

From the CDJFS perspective, it is apparent that the speed of Medicaid eligibility determination varies widely by county; and, within counties, it varies by worker. Among our thirty cases, the range of time between assessment and Medicaid eligibility determination was three days to three-and-one-half months, with a mean delay time of approximately 5.2 weeks. Again, our sample of thirty is non-representative. In our focus group of PAA site directors, participants reported average CDJFS delays ranging from thirty days to three-to-four months; most participants estimated the average in their PAA areas to be forty-five to sixty days.

From our interviews with assessors and case managers, with focus group participants, and with consumers and their caregivers, we conclude that delays in eligibility are unhealthy for consumers and caregivers, time-consuming for PAA professionals, and frustrating to consumers and professionals. By rule, if assessors have sufficient financial documentation to be reasonably confident of the consumer’s Medicaid eligibility, they can “presumptively enroll” the consumer and begin service delivery before eligibility is determined by the CDJFS. (At least one PAA does not exercise the presumptive enrollment option.) During the period of our data gathering, the presumptive enrollment option had been suspended and we observed some of the negative effects of that change from the consumer’s perspective. The option has since been restored.

Financial eligibility and informed choice

As stated earlier, the complexity of financial eligibility is another significant informed choice issue. Medicaid estate recovery is particularly complicated and sensitive, and although assessors provide basic information orally and in written materials, we did not observe CDJFS

interviews where the process of educating consumers continues; it would be helpful to examine the CDJFS eligibility determination system and process in a future evaluation.

Ongoing service plan and implementation

Do both service plan and service implementation match the individual's assessed needs and strengths?

We have concluded that the initial assessment process, as developed by the PASSPORT program and conducted by PASSPORT professionals, is sufficient to develop an initial service plan to address the most evident and immediate needs of the consumer. We have also identified challenges in facilitating consumer informed choice. We now turn to the effectiveness of ongoing service plans and service implementation in meeting the assessed needs of the consumers, or the “fit” between assessment and services. We examined whether services match needs in terms of: 1) **type** (Is the consumer getting *what* she needs?) 2) **amount** (Not too much and not too little?) 3) **quality** (Do services meet standards of good practice?) and 4) **impact** of services (How successful was PASSPORT at keeping care appropriately at home?).

We found that assessment is a moving target and the service plan is a necessarily flexible, adaptive response to changing needs and circumstances. As consumers' needs changed, types of services were added and subtracted; the amount of services was increased and decreased. Changes were very frequent in some cases and less so in others, but *all* case studies revealed a dynamic process of service plan modification.

Case management

Case managers are responsible for administering and monitoring the consumer's service plan; in that role, they are also responsible for the ongoing assessment of consumers. At the end of September 2006 case managers had an average caseload of 64 consumers. It is clear that the role of case management is the linchpin of the PASSPORT program and central to its success.

Case management, by design, implies a relationship between the case manager and the consumer [and her caregiver(s)], and the success of case management depends in large part on the trust and communication established within that relationship. We were impressed across the board with the responsiveness of case managers to their consumers' changing needs and circumstances.

As stated earlier, there are three levels of case management: consumer managed (requires case management contacts at least quarterly); supportive (requires at least quarterly contact and a face-to-face visit every six months); and intensive (requires at least monthly contact and a face-to-face visit every other month). The level is based on consumer needs and preferences, level of caregiver involvement, and input from the assessor and/or case manager. The level is negotiated with the consumer and caregiver(s) either at the time of the assessment or after a case manager has been assigned. Some of the PAAs exercise a policy of starting every consumer at the intensive level of case management, then adjusting the level as the consumer adjusts to the program. We are not able to conclude that one approach works better than another; we did not identify problems related to level of case management in any of our case studies.

From our review of case study documents, including case notes, we conclude that case managers appear to go beyond (often *well* beyond) the minimum contact requirements, especially in "complicated" cases. Consumers and their caregivers are encouraged to contact their case managers with questions, concerns, or requests related to their services and/or their own changing needs; case study case notes reveal that consumers and caregivers generally freely avail themselves of such open access to their case managers. In addition, direct service workers or other providers contact the case manager to report concerns or incidents. In fact, case management, as demonstrated by the professionals in our case studies, is part *care management* and part *crisis management*. Managing sudden, sometimes volatile changes, as well as more

subtle changes in the consumer's circumstances, requires case manager flexibility, organization, and good professional judgment, qualities we observed in all cases.

We observed examples of anticipatory crisis management, where case managers anticipated and prepared for a change in consumer needs. For example, one case manager, in partnership with Adult Protective Services and the consumer, worked with the consumer's local law enforcement agency to anticipate and consider strategies for handling crises with the consumer's daughter who resides with the consumer and has a history of disruptive behaviors related to a mental illness. Anticipating future needs is also evident in the case management of less crisis-filled consumer experiences. As we saw with Gina and Al at the beginning of this report, Gina's case manager is helping Al anticipate and plan for the possibility of nursing home placement should Gina's care needs come to exceed the capacity of Al and the PASSPORT program to sustain care at home.

We also observed examples of reacting/responding to unanticipated crises. For example, a consumer's informal care arrangement was abruptly changed when one of her caregiving daughters suffered a major stroke and PASSPORT services were increased accordingly.

All contacts with consumers are sources of assessment. Case managers are engaged in a shared, ongoing, and developmental process of assessment as the consumer's PASSPORT participation progresses. More and more sources of assessment input are incorporated into the assessment and the changing service plan of the consumer. Mechanisms of communication and feedback are important to this process and case notes reveal long and complex records of telephone and e-mail communications among involved parties.

Case management requires staying "on top" of, and documenting, many details, some seemingly small yet important to the consumer's quality of life. The level of detail that we saw is

remarkable. We read hundreds of case notations like this: “Consumer phone call to case manager: ‘I like the Poise pads but need them to be longer.’ Case manager to contact provider and send out a package of longer pads for consumer to try.” [One week later] “Consumer call to case manager: ‘The longer Poise pads worked better for me.’ Consumer requesting on a monthly basis. Consumer needs 2-3 pads daily. Case manager to authorize and arrange.”

Many times case managers were called to address an immediate need, for example: “Phone call from consumer concerning her friend is not able to transport her to Dr. appt. today at 9 a.m. and needs a ride. Instructed [her] that case manager will try to find transportation for consumer and will call back.” Next note, a few minutes later: “Phone call to [transportation service] concerning consumer needing transportation to Dr. office this a.m. for a 9 a.m. appt. [Service] stated that they will be able to pick up consumer and take her to appt. and will be at consumer’s home in ten minutes.”

Our evaluation also revealed several cases where case managers went “above and beyond,” for example when one case manager stopped at the consumer’s house late on a Friday afternoon to deliver a supply of Depends when it was discovered that the consumer was going to run out before the next scheduled delivery.

PASSPORT cannot succeed without the professionalism and diligence of its case managers. Nearly all consumers and caregivers expressed praise and gratitude for their case managers: “She is always there when I need her.” “If I need anything, she gets on it right away.” “I call her any time I have a question and she always has an answer.” These testimonials are supported by our examination of case management activity in documents and interviews. We found a negligible number of gaps or lapses in case management tasks.

Service delivery, case manager discretion, and consumer informed choice

A service plan is changed when a type of service is added or removed; when the provider and/or worker is changed; when hours or units of service are rescheduled, increased or decreased. Each of these changes represents a point of consumer choice and case manager discretion. As we have said, consumers and their caregivers appear to become increasingly program-savvy; and, they are more able to assess and articulate their own needs over the life of their PASSPORT careers.

Meanwhile, case managers exercise ongoing discretion in negotiating, approving, or denying requests for changes in services. Case management supervisors are important here. Case managers turn to their supervisors for consultation and for approval of service plan changes. Thus, case managers and supervisors exercise discretion and professional judgment on behalf of consumers; the checks-and-balance process among consumer, case manager, and supervisor appears to be effective.

PASSPORT consumers exercise choice about the type and amount of services they receive, within the guidance and approval of the program, and limited by the availability of service providers and workers. We examined whether services match needs in terms of: 1) **type** (Is the consumer getting *what* she needs?) 2) **amount** (Not too much and not too little?) 3) **quality** (Do services meet standards of good practice and are consumers satisfied?) and 4) **impact** of services (How successful was PASSPORT at keeping care appropriately at home?)

Type

Consumers and caregivers exercised the most preference in the area of type of service, seeking services that matched the consumer's ADL and IADL needs. They selected from the options presented to them by the assessor and/or case manager; options were limited by service availability (e.g., in some rural areas, adult day services [ADS] was not available, and not on the

table). Most consumers received the type(s) of service(s) needed and preferred; they were less likely to receive these services *when* they wanted or needed them, for example at particular times of day, or on evenings and weekends.

Amount

PASSPORT consumers in our case studies actively sought a service plan that best matched their levels of need and did not insist on excessive services. One 85 year-old consumer who had lost her vision suddenly at age 81, expressed a determination that PASSPORT services not dominate her daily life. She asked for the fewest services possible to keep her safe and healthy at home: “The amount I have is good because it doesn’t interfere with the things I want to do” such as participate in activities in her senior housing complex. One caregiver caring for a severely impaired husband said, “I could send him to adult day care five times a week, but he likes to be home, too.” She opted for three days of ADS each week.

Two of the disenrolled consumers in our sample voluntarily withdrew from the PASSPORT program when they decided, after a period of rehabilitation from falls, that they had improved enough to manage their own care. This decision was made in spite of a disincentive to disenroll: each of the women would lose her Medicaid status and access to medications without having to spend down their assets. Both, however, expressed an unwillingness to consume public resources when, as one said, “others needed it more.”

Quality and Service Providers

The quality of the PASSPORT program is only as good as the quality of the service providers, for the essence of the consumer’s PASSPORT experience is the receipt of services from day to day. Our review of case notes, interviews with case managers, and interviews with consumers and caregivers revealed that the quality of service providers and direct service

provision is variable. Although most consumers and caregivers express basic satisfaction with their service plan, nearly all tell of occasional problems with quality of service delivery. In describing the quality of in-home services, consumers and caregivers generally focused on 1) whether they were treated kindly and skillfully by their workers and 2) whether they could count on their workers to work as scheduled.

In many of our cases, the consumers and caregivers expressed great appreciation of and even fondness for their direct service workers. (One consumer said, “I praise my ‘girls’ all the time.” Another said, “[The worker] is like an angel sent to me.”) When quality problems existed, as they did to at least some degree in almost every one of our cases, the problems usually had to do with the unreliability or poor attitudes of direct service workers. One caregiver described having to confront a worker three times for yelling at the consumer. When consumers and caregivers had concerns about their providers and/or workers, they usually worked with their case managers to exercise their option to switch providers or ask for a change in workers.

The quality of home-delivered meals was generally described in terms of tastiness and reliability. The quality of transportation was generally reported in terms of reliability and the helpfulness of the driver. The quality of ADS was measured by the kindness and “caring” of the ADS staff and by the consumer’s comfort with the program as perceived by the caregiver. Consumers and their caregivers reported the most variability in the quality of home-delivered meals, but most were satisfied with meals, or exercised choice to change providers if available. One consumer cancelled home delivered meals because, although “delicious and nutritious,” the meals were “too predictable and monotonous. I like to pick and choose.” Transportation was generally described positively with a few exceptions related to reliability. Adult day services were described positively in the few cases where ADS was used.

In one of our case studies, in a one-year period, the consumer did not receive forty-one scheduled personal care and homemaking service visits. The most frequent reason cited in case notes was “[provider] unable to staff.” Other reasons included “worker quit” or “the aid called off.” One note said that the consumer “took the aid off the case.” Although in a few instances, hours were “made up,” by any standard, for this consumer, provider quality was a serious problem in that year of service. Although this problem was an outlier among our case studies, it demonstrates the need for effective quality assurance mechanisms in the oversight of provider service delivery. For a thorough discussion of this topic, see *Provider Processes*.

Consumers operate from a set of a Bill of Rights and Responsibilities that speak directly to quality of care and services; yet it can be difficult to exercise the right to voice complaints. The perceived ability to voice complaints is an important informed choice issue for consumers and their caregivers. Consumers often feel indebted to the program and the providers for the care they are receiving; some say they do not want to appear ungrateful; or they do not want bother the case manager “too often;” or they worry that they will alienate or anger their workers and strive to keep the relationship pleasant and non-confrontational.

Impact

What is the impact of PASSPORT services on the ability of consumers and caregivers to keep care appropriately at home? Our disenrolled-to-nursing-home case studies are especially instructive here, as illustrations of both the strengths and limits of the PASSPORT program. It is noteworthy that none of the consumers in our case studies who disenrolled to a nursing home left the program, even in part, due to dissatisfaction with quality of services. Even in cases where consumers reported some issues with quality of services, the consumers and their caregivers expressed the importance of the service plan in keeping care at home. Those who disenrolled

from the program in favor of nursing home placement did so after all efforts had been exhausted in the face of consumer and/or caregiver declines in capacity to sustain home care. Disenrollment to a nursing home occurred in all cases when a tipping point was reached, that is, when the need for twenty-four hour or more skilled care exceeded the capacity of PASSPORT services; when the caregiver's capacity had declined; and/or when the caregiver had reached his or her "limit." In most cases, consumers and caregivers demonstrated a remarkable determination to sustain care at home while keeping the nursing home option open.

The consumer who had experienced forty-one "no-shows" in a one-year period continued in the program for two years beyond that year. She moved into a nursing home after a fall. For this family, the fall was their tipping point; concerns and risks had accumulated until they concluded that the consumer could no longer remain safely at home. Although the consumer hoped that the placement would be temporary she ultimately deferred to her daughters' wishes that she move permanently to the nursing home. She said, "My one daughter decided and the other daughter went along with it. I gave up. I just told them, 'Okay, I'll have to move out then.' ...I can't really explain why I gave up. I couldn't find anybody to stay with me at night, and [this nursing home] had an opening." This consumer's case manager did not begin disenrollment proceedings until one month after nursing home placement, determined that all options remain open while the consumer adjusted to the nursing home. Case notes reveal the case manager's effort to honor the preferences of the consumer while respecting the concerns and limits of the daughters; she kept the consumer informed of her choices even as those choices narrowed.

All of our case studies reveal consumers and caregivers strongly determined to keep care at home. The impact of PASSPORT on this effort is obvious. Consumers and caregivers

interviewed were effusive in their praise of the program; they expressed gratitude with descriptors such as “life savers,” “a blessing,” “I couldn’t have done this without them,” and “*Please, don’t do away with the PASSPORT program.*” One caregiver said, “I feel like I have been very blessed with the people they have surrounded me with.”

The larger system of care: An effective interdependence

We began the discussion of our findings by describing the role of PASSPORT as one component of a larger system of care. We have also described the determination and efforts of caregivers to keep care appropriately at home. We have been inspired by the efforts of consumers to exercise the right and responsibility to self care as much as possible and for as long as possible. And we have acknowledged the multiple forms of other services that contribute to home and community based care. This is a remarkable interdependence, and PASSPORT appears to be vital to its effectiveness. Although consumers experience threats to informed choice, and although they are subjected to variability in service quality, we conclude that the PASSPORT assessment, service planning, service delivery, and case management processes work very well to provide a valued alternative to nursing home placement.

SUMMARY OF MAJOR FINDINGS AND IMPLICATIONS

1. Case management and case management supervision work well; consumers and their caregivers use their case managers appropriately and are grateful for their support. Case management is part care management and part crisis management. The level of detail and unpredictability of the demands of case management require a manageable caseload. The size and level of demand of particular caseloads should be closely monitored.
2. Assessment in the PASSPORT program is a shared, ongoing, and developmental process. Successful initial assessments capture enough information about the consumer’s strengths and needs, as well as the level of informal support, to institute an initial service plan. Ongoing assessment and service plan modification requires reliable systems of communication between providers/workers and case managers.

3. Even though case managers work extremely closely with family caregivers, PASSPORT assessments are consumer-based rather than family-based. Caregiver assessment is minimal. The process and function of a family-based assessment is worthy of exploration.
4. Threats to informed choice are inherent in consumer vulnerabilities and in the complexities of the PASSPORT program. Initial assessments are most effective when they do not overwhelm the consumer and caregiver(s); when the assessor uses clear, jargon-free language; and when written materials are kept to a minimum. Most consumers and their caregivers can be trusted to become increasingly program-savvy over time; early work with them should be limited to the fundamentals: eligibility requirements, Medicaid estate recovery, rights and responsibilities, and an initial service plan.
5. Assessors, case managers and case management supervisors use discretion in facilitating informed choice and in the implementation of a service plan. Training and professional development should sensitize professionals to their discretionary “powers” and to the related vulnerabilities of consumers.
6. PASSPORT assessments should include an explicit evaluation of the consumer’s capacity for informed decision making.
7. Provider and worker quality is variable and consumers do not have adequate information about quality to make an informed choice about their service providers. Assessors and case managers cannot facilitate fully informed choice without adequate provider quality measures.
8. Medicaid-eligibility delays in service onset are related in part to the volume of documentation demanded of consumers, but appear more often related to bureaucratic or worker delays at the CDJFS level. This serious issue requires systematic investigation.
9. Our evaluation did not look at consumer/family informed choice in the Medicaid-eligibility process at the CDJFS agency level. Because of its complexities and its significant implications for families we believe the process merits evaluation.
10. During the course of our evaluation we learned PASSPORT consumers who were enrolled via the Home First option had disenrolled in unanticipated numbers. We were unable to include this population in our assessment and services sample and believe an evaluation of the composition and fate of Home First enrollees-to-disenrollees should be conducted.

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