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for the state of Ohio

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# **Real Choices: A Caregiver Respite Strategy For The State of Ohio**

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## EXECUTIVE SUMMARY

The purpose of *Real Choices: A Caregiver Respite Strategy For The State of Ohio* was to determine the feasibility of restructuring the PASSPORT program to achieve caregiver respite. In order to do so we defined respite, determined the number of potential PASSPORT consumers for respite, and the costs and/or savings of restructuring the PASSPORT program to achieve respite.

Focus groups and key informant interviews were used to define respite. Our findings reflect two definitions of respite, as service and as outcome, and a definition of respite strategy. Respite as service is any intervention that changes the *nature* and/or reduces the *level* of the caregiver's caregiving activities. Respite as an outcome is providing relief that may help caregivers sustain care at home. Respite strategy incorporates *both* of these definitions and processes.

Focus group interviews not only revealed the complexity of defining respite but they also placed respite in the *context* of a broader, four-pronged objective shared by individuals, families, service providers, program planners, and policy makers: 1) *To keep care at home (and out of the nursing home); 2) for as long as possible and appropriate; 3) while maintaining optimal health and quality of life of both caregivers and care receivers; 4) while containing family and public costs.*

Respite is *one* important tool in achieving this objective. As we explored the feasibility of incorporating respite into PASSPORT services and benefits, we needed to understand its place in the dynamics of this broader objective so we developed a conceptual model, "Successful Care at Home: A Support Model". Our model introduces the concept of Activities of Daily Caregiving. The tasks of care at home, which we call Activities of Daily Caregiving (ADC), are shared by 1) the care receiver (self care); 2) the primary caregiver; 3) other friends/family in support of the caregiver (informal respite); and 4) formal services, that is, either brief institutional respite or home and community based service providers. We call this sharing of care the ADC arrangement.

Our conceptual model illustrates respite is a strategy to help sustain caregiver activities and potentially keep care at home. Critical to respite strategy are the care receiver, caregiver, other support for the caregiver, and formal

services. Like the definition of respite, as we explored the feasibility of incorporating respite into PASSPORT services we had to understand how many PASSPORT consumers have a caregiver and the impact of respite on the costs of formal services.

We determined:

- The majority of PASSPORT consumers have at least one active caregiver.
- By sustaining caregiver activities and potentially keeping care at home, the cost difference between keeping the PASSPORT consumer enrolled in PASSPORT in comparison to the average cost of nursing facility care are significant.
- Any additional investment in Ohio's respite strategy will save the state money in the future.

Based on our findings we propose a four component family-based respite strategy. The four components of the proposed PASSPORT respite strategy are: (1) Defacto Respite; (2) Defacto Respite Plus; (3) Institutionalize Respite Strategy; and (4) Real Choices. Defacto respite has already been incorporated into PASSPORT. The three additional components introduce a family-based approach to service plan development, flexibility, and consumer-direction culminating in "Real Choices". As we see it, "Real Choices" is a modest, no-strings-attached cash benefit or voucher program that is grounded in a systematic assessment of the primary caregivers needs, similar to the flexibility built into the "supplemental services" part of the National Family Caregiver Support Program. Cash benefits to purchase goods and services will help offset the often higher cost of other services and/or for some enabling the caregiver to continue support of the care receiver.

## **BACKGROUND**

PASSPORT, Ohio's home and community based services 1915c waiver program for income-eligible older adults, is a vital program for older adults requiring nursing home level of care, but who want to remain at home. Although some PASSPORT beneficiaries are able to stay at home without the informal support of friends or family, most require the assistance of informal caregivers, with the help of formal services, to keep care at home. Caregiving stress has long been recognized as an impediment to sustaining in-home care, and both families and the public have a vested interest in delaying or avoiding unwanted and unnecessary costly institutionalization.

PASSPORT services are designed to be delivered to the older person as the Medicaid beneficiary. By design, services are based primarily on attention to the participants needs, with minimal assessment of the caregiver.

Respite, "a caregiver relief support service," (Reinhard, Bemis & Huhtala, 2005) has not been a named service (under the 1915c waiver authority) of Ohio's PASSPORT program. Caregiver respite is one of the concerns addressed by the CMS Real Choice Systems Change Grants under the President's New Freedom Initiative. As a Real Choice Systems Change funded project we seek to answer the following question:

**What is the feasibility of restructuring the PASSPORT program to achieve caregiver respite?**

To answer this question we had to define respite, determine the number of potential PASSPORT consumers for respite, and consider the costs and or savings of restructuring the PASSPORT program to achieve respite.

We approached this project from perspectives gained in an earlier study (Applebaum, Kunkel, & McGrew, 2002) for the Administration on Aging's National Family Caregiver Support Program. In focus groups with caregivers and long-term care providers, we identified factors and dynamics that contribute to quality caregiver support, including respite. Because these findings strongly informed our approach in the current project, we summarize them here.

- There is an artificial, structurally entrenched, inefficient and sometimes counterproductive dividing line between caregiver support services and care receiver services. No matter how, why, or to whom we think we are delivering services (i.e.

to/for the caregiver or to/for the care receiver), nearly all services are received and experienced by families, not by the PASSPORT consumer only. The caregiver is part of a family system, yet because attention to caregiver needs came very late in the development of home-and-community-based services, caregiver support services became an add-on, and were funded and delivered as such. Sometimes the “add-on” has simply been an increase in services to the PASSPORT consumer.

- Respite always involves the care receiver and care receiver services always affect the caregiver. Both affect the family’s capacity to sustain care at home. At the very least, the amount and type of care receiver services affect how much and what type of respite a caregiver needs. We were struck by our finding that home delivered meals - delivered to care receivers - were experienced by many of the caregivers as a valued “respite”: they may allow time off and away, or, at the very least, they may free up how actual, designated respite hours are used meaningfully by caregivers. The array of formal services, including respite, are received and experienced by the family as a package whether or not they are delivered to them as such.
- It is important to look at respite as an outcome. This supports Chappell et al (2001) conclusion that “respite has been defacto conceptualized as a service rather than an outcome.” (p.201). It is important to look toward the outcome for the caregiver, in the context of the family’s objectives.
- Caregivers and their care receivers often have competing needs; a respite service that has a positive outcome for a caregiver may have a negative outcome for a care receiver and vice versa. What is the impact on the family as a whole when competing needs are not reconciled? What is the net effect of caregiver respite for individuals and the family as a whole? Services, whether “primarily” directed toward caregivers or care receivers, are family decisions, and assessment and implementation necessarily include a process of negotiating common and compatible goals toward the overall objective of sustaining family care. This family-centered perspective is consistent with findings from the 1997 national survey conducted by the National Alliance for Caregiving and AARP Family Caregiving in the U.S.: Findings from a National Survey (1997). The report recommends a family system approach to services.

- Each caregiver and family is different, and definitions of respite are personal and idiosyncratic. The formal caregiver support system may define respite as in-home respite, adult day care, overnight respite, and/or a combination of these services. In comparison, caregivers expand respite to include services like home delivered meals. This finding suggests the importance of consumer-directed respite services.
- Respite services can actually add to caregiver strain and burden because even as they are designed to provide support, they may introduce stressors and costs. Potential stressors include added pressure for family negotiations and decision making, a fixed or altered schedule or routine, intrusion of “strangers” into the family life and household, an unhappy care receiver, and worry about service quality. Potential costs include time, energy, family conflict, privacy (social, physical, and financial), dignity, control, threats to independence, autonomy, personal savings, employment, and employment income.
- Services are experienced in stages, and respite need is a moving target. Changes in care receiver and/or caregiver health status, in family dynamics or resources, and in the cumulative effects of family care create changes in respite needs. Services may lag behind changing respite need.
- A respite service is unlikely to sustain family caregiving unless it is experienced as true respite. Simple “time away” does not extend the caregiver’s capacity to provide care; a “break” does not by itself reduce the level of strain and burden. We must conceptualize true respite as the desired outcome.
- PASSPORT consumers by definition have limited financial resources; they also represent a higher proportion of racial and ethnic minorities among caregiving families. It is important to design services that are sensitive to economic circumstances and that are culturally competent.

## **DEFINITION OF RESPITE**

Focus groups and key informant interviews were used to define respite. We conducted seven focus groups, in both urban and rural areas across the state.

- Three caregiver groups (n=25)
- One care receiver group (n=4)
- Two care management agency staff groups (n=10) ( mix of case managers and program managers)
- One National Family Caregiver Support Program direct service provider group (n=7)

The twenty-five caregiver participants included five males and 19 females, from age 29 to age 92, nine of the caregivers were African-American, 12 were daughters, seven wives, three husbands, one son, one son-in-law, and one sibling. Most of the caregivers lived with their care receivers. The duration of caregiving ranged from six months to 26 years.

The care receiver group was composed of two men and two women. All but one of the women, who lives with her daughter, received care from spouses.

One of the care management agency staff groups was conducted with a particular focus on ethnic issues. The four PASSPORT case managers in this group served an urban area and had racially and ethnically diverse caseloads. All of these professionals happened to have immigrated to the U.S. and themselves had non-dominant ethnic backgrounds.

We also conducted key informant interviews. Two key informants were national respite advocates, from the National Respite Coalition and the Easter Seal Society. Another key informant was a respite program coordinator from a neighboring state. These key informants were used to refine questions for focus group interviews before they began. The remaining key informants were an advisory council, three National Family Caregiver Support Program (NFCSP) coordinators, case managers from each Area Agency on Aging (AAA), one PASSPORT clinical director, and several representatives from Ohio Department on Aging (ODA.).

We asked the focus groups and key informants to define respite. Not surprisingly, there was no clear consensus definition. Rather, the wide array of definitions supports



the proposition that the need for respite and the type that is preferred is personal and idiosyncratic. These multiple definitions reflect an inconsistency in services philosophy and delivery. They also reflect the ambiguity in CMS language related to respite. Such conceptual and regulatory issues are well-documented in a discussion paper from Community Living Exchange on defining respite care (Reinhard, Bemis & Huhtala, 2005). Finally, inconsistencies in the conception and delivery of respite are found not only across the state, but also within counties, agencies, and programs.

Most inconsistencies in defining respite had to do with which formal services “count” as respite and with allowable uses (e.g. to go to work) and eligibility for (e.g. caregivers or care receiver) respite. Many participants reflected a narrow conception of respite to include adult day services or companion services only. Some conceived of traditional care receiver services as respite services. (*Any service, meals, personal care, homemaking, nursing facility respite, etc. that provides the caregiver with an opportunity to take a break from their caregiving responsibilities.*) Professionals more often than not included a conception of respite as *outcome* in their definitions.

Our findings reflect two definitions of respite, as service and as outcome. Each is legitimate, but respite as service is the mechanism for respite as outcome.

We know that respite as an outcome has been achieved if the caregiver experiences some or all of the following:

- Reduced physical and emotional strain. (If this isn’t happening, it’s not true respite.) Individuals can identify when they feel relieved and restored. One caregiver said, “If it hadn’t been for that day care and the respite care, I’d have been dead a long time ago.”
- Resumption or maintenance of social roles, activities. (School, work, family, friends)
- Improved relationship between caregiver and care receiver.

We now turn to the distinction and relationship between service and outcome, and propose the following:

**Definition of respite as service:** any intervention that changes the *nature* and/or reduces the *level* of the caregiver's caregiving activities.

**Definition of respite as outcome:** providing relief that may help caregivers sustain care at home.

**A Respite Strategy incorporates *both* of these definitions and processes.** With a respite strategy, person-centered, meaningful changes in the nature and/or level of caregiving activities reduce caregiving stress.

### **DEFINITION OF RESPITE: UNDERSTANDING THE DEFINITION**

Focus group interviews not only revealed the complexity of defining respite but they also placed respite in the *context* of a broader, four-pronged objective shared by individuals, families, service providers, program planners, and policy makers: 1) *To keep care at home (and out of the nursing home);* 2) *for as long as possible and appropriate;* 3) *while maintaining optimal health and quality of life of both caregivers and care receivers;* 4) *while containing family and public costs.*

Respite is *one* important tool in achieving this objective. As we explore the feasibility of incorporating respite into PASSPORT services and benefits, we need to understand its place in the dynamics of this broader objective. In order to do so we developed a conceptual model, "Successful Care at Home: A Support Model," to:

- recognize the roles of *all* actors in keeping care at home, including the role of the care receiver
- recognize the different circumstances, needs, and preferences of individuals and families
- introduce and employ the concept of Activities of Daily Caregiving
- identify the effects of both the stress of caregiving and the strengths of caregivers and other actors
- emphasize the role and importance of respite in reducing stress
- define respite as both service and outcome
- introduce and employ the concept of a respite strategy (linking service to outcome)

- distinguish a respite strategy from other caregiver support services
- identify the role and importance of other caregiver support services in increasing strength
- illustrate the combined impact of a respite strategy and other caregiver support services
- identify successful care at home as an ultimate outcome achieved through a respite strategy and other caregiver support services
- illustrate the impact of all services on all family members
- bring about a family-based, person-centered, flexible respite strategy to keep successful care at home.
- advocate a consumer-direction option
- advocate an integration of care receiver and caregiver service systems

This model may be applied to either caregiver, care receiver, or the family as a unit. To introduce the model and to maintain our focus on caregiver respite, we apply the model to the caregiver in the greater part of this report.

“Successful Care at Home: A Support Model” introduces the concept of Activities of Daily Caregiving. The tasks of care at home, which we call Activities of Daily Caregiving (ADCs), are shared by 1) the care receiver (self care); 2) the primary caregiver; 3) other friends/family in support of the caregiver (informal respite); and 4) formal services, that is, either brief institutional respite or home and community based service (I/HCBS) providers. We call this sharing of care the ADC arrangement. (Who does what care, when, where, why, and how much?)

Activities of Daily Caregiving (ADCs) have a direct association with ADLs, or Activities of Daily Living. For the purpose of this report, “ADLs” is used generically to include personal care, e.g. bathing, toileting, eating; and instrumental care, e.g. meal preparation and housekeeping. Activities of Daily Caregiving are the tasks performed by others to compensate for ADL limitations of the care receiver. “Others” include informal caregivers, including the primary caregiver and informal respite supports (secondary caregivers); and formal providers of brief-institutional respite or home and community based services. ADCs include not only ADL based tasks such as bathing and meal

preparation, but also supervision and companionship needed by individuals with cognitive impairments. Self care is the care “receiver” performance of ADLs and also includes the level of independence for supervision. It is important to note that Activities of Daily Caregiving may not actually be performed daily, but are the somewhat regular activities and tasks necessary to keep care at home.

ADCs can reflect strength or stress. We make a conceptual argument that care can be successfully done at home only when caregiver strength is at least equal to the stress of caregiving, or, said another way, when caregiving stress does not exceed caregiving strength. Necessary characteristics of a successful outcome include delaying or avoiding institutionalization, maintaining the optimal physical and emotional health of both caregivers and care receivers, maintained or improved relationships between caregivers and care receivers, maintained or reduced family and public financial costs. When stress exceeds strength, a negative outcome is produced. Characteristics of a negative outcome include premature or unnecessary institutionalization, physical and/or emotional illness or impairments, strained or damaged relationships, and/or excessive family or public financial costs. Strengths and stress are in a constant state of change and “outcome” is therefore inherently unstable. This calls for continuing efforts to keep stress low and strengths high.

Other studies have addressed the relationship between caregiver stress and caregiver resources. Zarit, Todd, and Zarit (1986) found that individuals with dementia were at greater risk of institutionalization when the cumulative demands on their spousal caregivers exceeded caregiver resources. We look at the impact of the intersection of strength and stress levels on efforts to keep care at home. We then identify the role of respite in reducing stress and other caregiver support services in increasing strength to keep care at home, with a focus on the role of respite.

Caregivers bring a unique set of strengths and limitations, or level of strength, to the demands of ADCs. We call this ADC Strength. ADC Strength includes the following resources: physical, cognitive, emotional, spiritual, attitudinal/motivational, knowledge, skills, time, financial, physical, environmental, and social supports. Even as caregivers bring strength to ADCs, strength is taxed. Both the demands and rewards of ADCs combine to produce a level of stress, called ADC Stress. ADC Stress includes a

set of exertions [physical, cognitive, emotional/spiritual]; expenses [social roles, social activities, financial]; infringements [privacy/autonomy, time, routine, relationships]; aversions [task-specific, relationship-specific, culture-specific]; and stress modifiers (rewards and satisfaction).

We ultimately argue that there are two approaches to supporting care at home: 1) A Respite Strategy to reduce ADC Stress and, 2) Other Support Services to increase ADC Strength. In this way, we distinguish a respite strategy from other forms of caregiver support. *Both* are essential to producing a successful outcome.

Examples of interventions in a respite strategy to reduce ADC Stress include occupational therapy or technological and assistive devices to increase the self care capacity of the care receiver; methods to increase or otherwise change the participation of secondary caregivers (informal respite); and the use of brief institutional or home and community based services. To reduce stress, choices about who gives what care, when, where, and why, must be person-centered and family negotiated.

Other Support Services do not reduce the demands presented by ADCs; that is the role of respite. Instead, Other Support Services address the strengths required to meet those ADC demands. Examples of Other Support Services that increase or maintain ADC Strength include support groups, counseling, education, information and referral, skills training, strength-building and restorative care, health promotion and care, financial support, and housing and home modifications.

We offer the following vignette to illustrate how our conceptual model works.

## **Karen and Arla: A Negative Outcome Example and Figure 1**

Karen, one of our focus group participants, has been caring for her mother, Arla, who has dementia, for ten years. Karen describes life at home in the nine years before they received services.

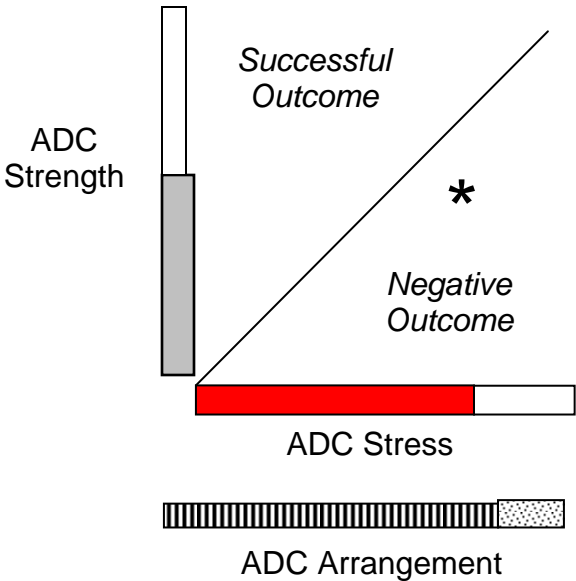
*I was only 26 years old when I first started taking care of my mom and to be quite honest, I didn't have my life together yet and it was really tough. I'm the youngest out of nine kids and I knew my mom would not do well in a nursing home setting. She would just decline and I...so I decided to bring her home and she did get better, but as the years went on, the less help [from my siblings] I got, and it's like I had to put everything on hold. My life, you know, my son suffered. When he got old enough, he had to help take care of her. I didn't have anybody and I mean I had to put my school off. I had to drop down to part time. I mean I lived like a pauper forever because I just didn't know how to access any of these services.*

*[I]t got to a point where she was almost comatose. She'd just sit all day. She wouldn't even watch TV. TV would just watch her. I was so busy. I couldn't get out and do things, you know, help her and get out and go places and do ....you know, we would go places, but you know certain things I just couldn't....It had got to a point where I just couldn't give her care. I was exhausted. I was tired. I was stressed out. I just...I was almost about to lose my mind actually....*

Outcome:

- Karen's ADC Stress exceeds her ADC Strength.
- There is no respite strategy. (The ADC arrangement consists of Karen and Arla only.)
- There are no other support services.
- Quality of life suffers for both Karen and Arla.
- Arla is at risk of nursing home placement.

**Figure 1**  
**Successful Care at Home: A Support Model**  
 (Negative Outcome)  
 Karen and Arla



- Caregiver
- Informal Respite
- I/HCBS
- Self Care

## **Karen and Arla: A Positive Outcome Example and Figure 2**

Karen describes the process and outcome of placing her mother in adult day services.

*I just found out about [adult day services] about eight months ago and it has been a tremendous load [off]. [I]n the beginning, [mother] didn't want to go... I had to beg her and beg her and beg her to get out of that bed,... it would take me forever to get her out of that bed and then when ... she heard the door bell and she opened the door....oh, hi baby. And she'd be just as nice and peachy and I'm sitting here with tears running all the way down my face and they don't understand what's going on. But she loves it now. She really loves it.*

*[It] has helped her because she... and I just did not want to put her there because ...and I felt the guilt. I was so guilt ridden. I just could not do it and I knew she...it got to a point that she wasn't even getting the care that she deserved anymore because I couldn't give it to her, but I still could not make that decision and then I had the family...no, you don't want to put her in a ....but then they wouldn't help, you know. And so this was like a godsend. For me it was the greatest thing because I had to come to realize that I wasn't taking care of myself. If I can't take care of me, I can't take care of [her], and that was the bottom line and it was an alternative [to] going to the nursing home....*

*[At adult day service], if they have a little time, they bake cookies. Sometimes I don't have the patience to do that with her. I'm serious, you know. If ... it's taken all day to get her up..."No, I don't want to bake any cookies. I just want to lay here mom. Just leave me alone." It's sad to say, but I get aggravated a lot and I can't care for her in those ways.*

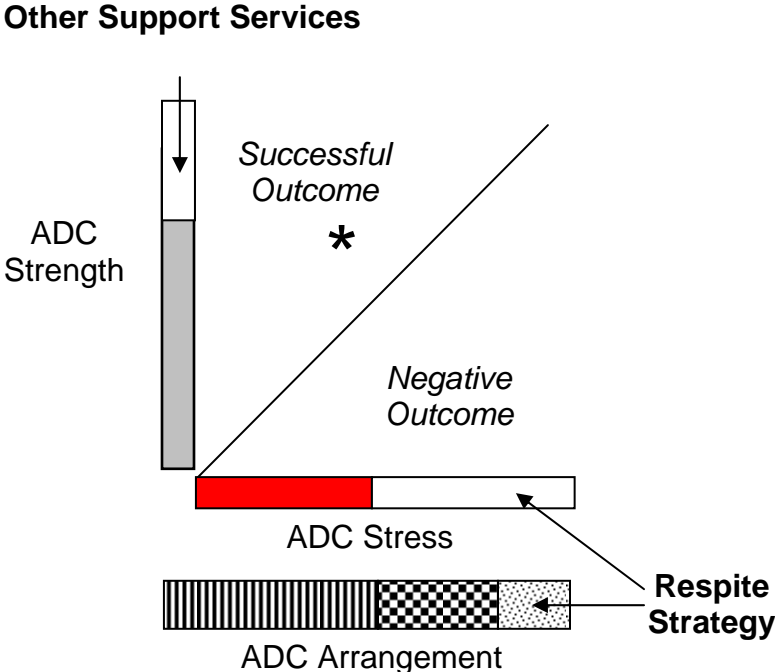
*... I just finished my first year in college so it's helped me do a lot and that's the break that I needed. I knew she was getting taken care of and I could go and do the things that I needed to do and that's what I needed..*

Outcome:

- Karen's ADC Stress is reduced by intervention in the ADC arrangement (providing adult day service).
- The ADC arrangement now consists of Arla, Karen and adult day service.
- The nature and level of Karen's ADCs are meaningfully changed to reduce ADC Stress.
- Her ADC Stress no longer exceeds her ADC Strength.
- Physical and emotional health are preserved.
- Quality of life is improved for both Karen and Arla.
- Successful care at home is maintained.



**Figure 2**  
**Successful Care at Home: A Support Model**  
 (Successful Outcome)  
 Karen and Arla



- Caregiver
- Informal Respite
- I/HCBS
- Self Care

## **PASSPORT CAREGIVERS AND SERVICE PLAN COSTS**

As you can see from the vignette, respite is a strategy to help sustain caregiver activities and potentially keep care at home. Critical to respite strategy are the care receiver, caregiver, other support for the caregiver, and formal services. Like the definition of respite, as we explore the feasibility of incorporating respite into PASSPORT services we need to understand how many PASSPORT consumers have a caregiver, some of the characteristics of PASSPORT caregivers, the services PASSPORT caregivers provide, and the impact on the costs of formal services.

An analysis of a PASSPORT data for State Fiscal Year (SFY) 2003 (July 1, 2003 to June 30, 2004) was completed to determine the number of PASSPORT consumers who have active caregivers, to develop a profile of PASSPORT consumer caregivers, to examine conditions associated with the level of caregiving and caregivers' functional status, and the assess impact current practices have on service plan costs. (PASSPORT data from all Area Agencies on Aging that completed the integration of the PASSPORT system redesign as of July 2003)

Table 1 presents the percentages of PASSPORT consumers who do not have a caregiver, percentage of PASSPORT consumers who have at least one caregiver, and percentage of PASSPORT consumers who have more than one caregiver.

<b>Table 1</b>	
<b>Percentage of PASSPORT Consumers Who Have a Caregiver</b>	
	<b>Percentage</b>
Consumer with No Caregiver(s)	31.7
Consumer with One Caregiver	54.8
Consumer with Two Caregivers	13.5

The majority of PASSPORT consumers have at least one active caregiver (68.3%). This proportion is extremely close to the estimates we received from PASSPORT case managers across the state. Case managers estimated an average of 68.9% of their consumers have caregivers.

In addition to determining the number of PASSPORT consumers who have active caregivers we also developed a profile of PASSPORT consumer caregivers and the services they provide.

Demographic and health status of PASSPORT caregivers include:

- Sixty-eight percent of the caregivers are married.
- Almost sixty-nine percent of the caregivers are female.
- The vast majority (89%) of the PASSPORT caregivers are either a spouse or other relative.
- Virtually no PASSPORT caregivers (99%) were trained to be a caregiver.
- On a scale from poor to excellent, caregivers perceived physical health is good (57%) while one in three rate their health as fair.
- Sixty-eight percent feel their emotional health is good. Like perceived physical health, very few feel their emotional health is excellent (5% and 6%, respectively).
- Seventy-five percent of the PASSPORT caregivers live with the care recipient.
- Over half (56%) of the caregivers were employed either full or part time.

Table 2 presents the ways and extent of caregiver support for PASSPORT consumers.

**Table 2**  
**Caregivers Assistance to PASSPORT Consumers**  
**June 2004**

Activities	Percentages
Emotional support	48.6
Transportation	36.2
Shopping	36.5
Meal preparation	28.3
Chores/Yardwork	24.2
Money management	26.6
Housekeeping	23.0
Laundry	17.1
Personal care	20.4
Supervision	18.6
Medication setup and administration	8.7
Respite	1.3

Service plan costs are costs associated with services ordered by a PASSPORT case manager for PASSPORT consumers. The average annual service plan cost for PASSPORT consumers in SFY 2003 is \$12,785. In Ohio, like other states, PASSPORT consumers do not use all of their authorized service plan hours. For instance, in the evaluation of cash and counseling program in Arkansas, traditional agency service users (like PASSPORT users) received about 70 percent of the authorized service plan hours (Doty, 2004). This occurs for a number of reasons. In some cases the provider agency is unable to provide the authorized service because of organizational barriers like insufficient labor. In other cases, the consumer elects to forgo the service for personal reasons such as illness and/or vacation. Other evidence suggests Ohio's actual program expenditures are approximately 20-25 percent less than authorized service plan costs and

the gap between authorized and actual service plan cost increases when overall service plan costs are higher.

It should be no surprise that level of impairment has a direct correlation with PASSPORT service plan costs. The data indicate that over thirty percent of the variance in service plan cost is related to activities of daily living (ADLs). Higher levels of ADL impairment, for dressing, eating, grooming, and especially toileting increase the cost of service.

### **SERVICE PLAN COSTS: THE FINANCIAL IMPACT OF RESPITE**

Assuming that the availability of a viable respite strategy would help sustain informal caregivers and prevent or postpone more costly nursing facility placements we created a model to attempt to measure the financial implications of overburdened caregivers who are no longer able to cope with their ADCs in the community setting. Our model is based on levels of impairment, plan service costs, and disenrollment data.

First, we identified the percentage of PASSPORT consumers who have the same level of impairment as persons living in nursing facilities. In a recent comparison of the demographic and functional characteristics of Ohio nursing facilities residents and PASSPORT consumers, the difference in the average number of ADL impairments between the PASSPORT and nursing facilities population were 3 and 4.5, respectively (Mehdizadeh and Applebaum, 2003). Further, there are marked differences in the percentage of PASSPORT consumers and nursing facility residents' needs for assistance in ADLs, particularly for dressing, toileting, eating, and grooming. Using these benchmarks to guide us we developed two scenarios. The first scenario isolates the number of PASSPORT consumers with 4 or more ADL impairments (general ADL group). The second scenario identifies the percentage of PASSPORT consumers who need hands on service for all four critical ADL impairments (dressing, toileting, eating, and grooming) (critical ADL group). For scenario one and two, we find 32 percent of the PASSPORT population fall into the general ADL group, and 8.2 percent of PASSPORT consumers fall into the critical ADL group. A summary of these steps is presented in Table 3.

**Table 3**  
**Comparison of General to Critical ADL Groups**

	<b>General ADL Group</b>	<b>Critical ADL Group</b>
ADL impairments	Four of: Mobility, Bathing, Grooming, Toileting, Dressing, Eating	Including all of: Dressing, Toileting, Eating, Grooming
Percent of PASSPORT Population	32	8
Estimated Service Plan Costs	\$14,871	\$17,488
Average Cost of Nursing Home	\$58,035	\$58,035

Next, we calculated the annual average service plan costs for each group. Again, these are estimated service plan costs based on authorized services. For the general ADL group, the average cost of a service plan per consumer per year is \$14,871. For the critical ADL group the average cost of a service plan is \$17,488.

Third, we determined the Ohio average annual cost of nursing facility service. According to Applebaum and Mehdizadeh (2005), the average cost of nursing home service per day is \$159.00 or \$58,035 per year.

Fourth, to estimate the potential costs of any addition to the State of Ohio's current approach to respite, an estimate of the number of PASSPORT consumers for current and additional interventions must be calculated. To complete this task the following steps were taken.

- 1) We used 2000 thru 2020 US Census data and Scripps population projections to determine the actual and projected total population (60 and over).

- 2) To determine the number of persons (60 and over) who meet the PASSPORT level of service threshold we used Scripps projections of the severely disabled population by county.
- 3) To determine the number of persons (60 and over) who are severely disabled and meet PASSPORT financial eligibility criteria we used the US Census long-form question on income. If a person's income (sum of Social Security, SSI, Pension, Wages, Self-employment income, Public assistance, and Other income) is \$1,300 or less a month that person is considered meeting financial eligibility.
- 4) Not all of the projected numbers of persons (60 and over) eligible for PASSPORT will use the program, so we had to project PASSPORT utilization. We calculated utilization rates using unduplicated annual PASSPORT consumers divided by the number of PASSPORT eligible persons (60 and over) for SFY 2004. The average utilization rate is 23.84 percent. An alternate approach to calculating the number of persons who would use the PASSPORT program is to compare average daily PASSPORT census to the number of PASSPORT eligible persons (60 and over) over the same time period. If this approach is used the number of PASSPORT consumers with active caregivers is 29 percent smaller.
- 5) To determine the number of PASSPORT eligible and participating consumers who have active caregivers we used the percentage of PASSPORT consumers who had at least one active caregiver. Like the estimates of utilization, these percentages represent the unduplicated annual PASSPORT consumer and not the number of persons (60 and over) participating in the PASSPORT program at any given time.

Table 3 presents our estimate of the number of PASSPORT consumers assuming no changes in the State of Ohio's eligibility criteria for PASSPORT.

**Table 4**  
**Number of PASSPORT Consumers and PASSPORT**  
**Eligible Consumers With at Least One Caregiver 2005-2020**

<b>Year</b>	<b>PASSPORT Consumers*</b>	<b>With Caregiver*</b>
2005	31,941	21,816
2010	34,190	23,352
2015	36,668	25,044
2020	39,813	27,192

\*Unduplicated annual PASSPORT Consumer

Finally, we calculated the potential costs and savings of keeping each group of PASSPORT consumers in the community. The results are presented in Table 5.

**Table 5**  
**Potential Costs and Savings of Keeping PASSPORT**  
**Consumers with Caregiver in the Community in 2005**

	<b>General ADL Group</b>	<b>Critical ADL Group</b>
Number of Projected PASSPORT Consumers	6,981	1,789
Number of Projected PASSPORT Consumers Disenrolled to Nursing Home	1,885	340
Cost if Disenrolled	\$109,395,975	\$19,731,900
Cost if Not Disenrolled	\$28,031,835	\$5,945,920
Potential Savings	\$81,364,140	\$13,785,980



This step in the analysis was based on the number of projected PASSPORT consumers with an active caregiver in 2005 and the likelihood that the consumer would disenroll from PASSPORT to a nursing facility. The disenrollment rates for the general ADL and critical ADL group are 27 percent and 19 percent, respectively. Our model projects the cost difference between keeping the PASSPORT consumer enrolled in PASSPORT in comparison to the average cost of nursing facility care is approximately \$14 million for the most impaired consumers (critical ADL group), and approximately a \$80 million in savings for those with as many or more ADL impairments (general ADL group). Regardless of which, if either, of these scenarios occur it appears any additional investment in Ohio's respite strategy will save the state money in the future.

### **IMPLEMENTING A RESPITE STRATEGY**

Based on the outcome of our independent research, the qualitative steps used to define respite, our conceptual framework for understanding a respite strategy, the number of PASSPORT consumers, and the results of our PASSPORT analysis, we propose a four part family-based respite strategy.

To successfully keep consumers at home, PASSPORT must involve families in service planning and delivery. In providing home and community based services, even institutional respite services, a common question asked is "Who is the client/consumer?" If we instead first ask, "What is the objective?" (How do we keep consumers at home with optimal health and quality of life for all involved, while containing costs?).

Our findings strongly indicate support for a family-based approach to keeping consumers at home. If keeping the participant at home is our objective, the family as a unit is the clear target for intervention. To attend equally to the needs of the care receiver and the caregiver, and when we work to reconcile those needs in one strategy, requires a family-based approach.

What do we mean by family? This is a sensitive issue, and our use of the term family may reinforce an unnecessarily narrow conception and practice. Therefore, a disclaimer is in order. We know that the definition and composition of families varies widely. In fact, many families or informal support networks are not related at all. A "family" may be a close network of friends and/or neighbors, either with a long history,

or rallied around a particular need. Unmarried individuals in a relationship of mutual support are also the “family” who provide long-term care at home. For purposes of this report, “family” subsumes all of these definitions.

Caregiving families may be co-residential, or they may live apart. They may have more than one care receiver and/or more than one caregiver. Caregivers may give 24-hour care or occasional care. We assume that all are vulnerable to caregiving stress.

### **RESPIRE IMPLEMENTATION PLAN**

The four components of the proposed PASSPORT respite implementation plan are: (1) Defacto Respite; (2) Defacto Respite Plus; (3) Institutionalize Respite Strategy; and (4) Real Choices. Defacto respite has already been incorporated into PASSPORT. The remaining three parts will require additional resources.

Defacto Respite: In reality, and without a waiver, respite has already been incorporated into the PASSPORT program in different ways depending on the Area Agency on Aging, particular assessor(s) and/or case managers. Caregiver respite is being provided using PASSPORT “care receiver” services either incidentally or intentionally. Incidental respite occurs when a service is arranged primarily to benefit the care receiver and only incidentally achieves a respite outcome for the caregiver. Intentional respite occurs when a care receiver service is arranged either to achieve a dual outcome (care for the care receiver and relief for the caregiver) or to relieve the caregiver primarily to reduce caregiver stress to keep care at home.

When a case manager uses Ohio’s PASSPORT program services like assistive technology, service management, meals, emergency response, home modifications and repair, homemaker, chore, personal service, transportation, adult day service services they achieve a respite outcome for care receivers and caregivers. When a PASSPORT consumer receives these services their respective caregivers(s) are relieved from providing a similar service. We call this defacto respite.

The problem with defacto respite is there is no consistency across the state resulting in great unevenness in services and service options. Some service managers view respite as an outcome of each and every service they order for their PASSPORT

consumer. Others limit their definition of respite to a finite number of services, like adult day service, and subscribe services solely based on the PASSPORT consumer.

Another issue, at least as recorded in the PASSPORT assessment, is that there is minimal assessment of the needs of the caregiver. The state has redesigned the assessment process to better record the ability of caregivers to provide service, service duration, service frequency, caregivers' demographic information, caregivers' mental health, caregiver's physical health, caregivers' strain, and willingness and ability of caregivers to provide service. Steps are now being taken to see that PASSPORT case managers/assessors complete the caregiver assessment portion of the PASSPORT assessment and to consider on a more routine basis the needs of the caregivers. Although important changes, the PASSPORT assessment process continues to assess whether the caregiver is willing and able to provide care, instead of assessing the caregivers' own particular needs. PASSPORT still does not legitimize the value of respite as a formal part of the plan of care.

The next three components to implementing PASSPORT respite attempt to build on the selected following principles established by a collaborative group of family caregiver advocates (National Alliance for Caregiving, 2003).

- 1) Family caregiving concerns must be a central part of health service, long-term care, and social service policymaking.
- 2) Family caregivers must be protected against the financial, physical, and emotional consequences of caregiving that can put their own health and well-being in jeopardy.
- 3) Family caregivers must have access to affordable, readily available, high quality respite care as a key part of the supportive services network.
- 4) Family caregivers must have appropriate, timely, and ongoing education and training in order to successfully meet their caregiving responsibilities and to be advocates for their loved ones across care settings. (Applies to Other Support Services, as opposed to a respite strategy.)
- 5) Family caregivers and their loved ones must have affordable, readily available, high quality, comprehensive services that are coordinated across all care settings.
- 6) Family caregivers and their loved ones must be assured of an affordable, well qualified, and sustainable workforce across all care settings.
- 7) Family caregivers must have access to regular comprehensive assessments of their caregiving situation to determine what assistance they may require.

The final three components to implementing a more effective PASSPORT Respite strategy are Defacto Respite Plus, Institutionalize Respite, and Real Choices. These components address changes in operational requirements, respite as a legitimate PASSPORT service outcome, the need for a family-based approach to service planning, build on an existing infrastructure, and consumer control, choice, and flexibility as part of the ultimate solution. They also recognize some of the barriers to future program development such as increasing demand and consumer preference for home and community-based services, financial pressures on new program development, coordination and integration of caregiver support into PASSPORT services, the paradigm shift PASSPORT case managers will have to make, and uniform assessment of caregivers in both the National Family Caregiver Support Program (NFCSP) and PASSPORT. Defacto Respite Plus, Institutionalize Respite, and Real Choices are presented in an order we believe will take PASSPORT respite from what it is today to where it could be in the future.

Defacto Respite Plus: The second component of the PASSPORT Respite plan is to add respite strategy training to current PASSPORT practices. The Ohio Department of Aging (ODA), in coordination with PASSPORT Administrative Agencies (PAAs), train key clinical and social service managers from each of the PAAs on selected topics. ODA, in coordination with the PAAs, is responsible for establishing changes in PAA operational requirements and the PAAs are primarily responsible for implementing changes in the field. The goal of the training is to establish consistency in PASSPORT practices across the state and ultimately make a significant contribution to PASSPORT consumer's health and welfare. According to ODA, the cost of this initiative is immaterial, in the context of the operating budget for PASSPORT, and the model appears to be well received by the PAAs.

We propose that ODA add respite to the list of selected topics. Using materials from this study, training could be developed for care managers across the state. Both ADC Strength and ADC Stress are measurable and reportable. Most caregivers could self report the strength they bring to the ADC situation on a scale of one to ten (ten being the highest) and could self report the ADC stress they experience on a scale of one to ten (ten being the highest). Care managers could then identify their particular ADC Strength

to ADC Stress “ratio” and therefore identify their particular level of risk for a negative outcome. Most important for professionals is the recognition of the dynamics of this model as they assess, negotiate, arrange and provide services for families. We acknowledge that such an approach to assessment and service delivery is untested, but believe that conceptually the ADC Strength/ADC Stress/Outcome model provides indications for a respite strategy and other support services provided in a comprehensive service plan.

Although we have focused on the application of the support model to the caregiver, it can be applied to the care receiver as well, and thus to the family as a unit. Care receivers bring a set of strengths to the care situation and they also experience the stress of the ADC arrangement. A successful outcome is achieved when the intersection of ADC Strength and ADC Stress is on the successful outcome side of the model for caregiver(s) and care receiver(s) in a family or other informal support network.

This training would meet two objectives. First, it would begin to sanction respite as a legitimate PASSPORT service outcome and shift the current “respite means different things to different people” culture to a much clearer definition. The training would also allow ODA to introduce the concept of a family-based approach to service plan development.

Institutionalize Respite Strategy: Using the existing range of services, benefits, and resources, the third component of the PASSPORT respite plan moves current practices to a more institutionalized model. Fienberg (2001) offers eight principles to guide systems integration of support services for family caregivers. Three of these principles are applicable to systematically integrating respite into PASSPORT. First, PASSPORT has to recognize and support caregivers as legitimate consumers in long-term care. PASSPORT does, in an inconsistent way, recognize and support caregivers but because PASSPORT and other HCBS waiver programs are not technically caregiver support programs, the system is structured with the care recipient as the primary beneficiary.

Second, a family-based, person-centered approach to assessment must be used (and incorporated into the Management Information System). We propose moving to a family-based approach to service planning and delivery. Doing so will help establish

respite as a legitimate PASSPORT outcome and assist with the paradigm shift that will be required at the state and local level. Program designers, PASSPORT assessors and case managers, and even providers will be asked to think about support and services in a whole new way.

Service planning with families will be challenging. *Case managers* discussed the challenges of negotiating a service plan with families.

*“If the caregiver needs relief, two hours on Monday, and the client refuses... the consumer refuses that... there isn’t a way to force the issue..... if the consumer is their own guardian and signs their own release...But we’ve always allowed the consumer the right to choose. And we’ve never been forceful about care and I think it would be an infringement on their rights.”*

*“That’s when I find, like, I’m in the middle of it. I’m trying to help the caregiver but I’m trying to respect the client’s rights and kind of, going back and forth. And I feel like I’m dancing, you know, because I’m trying to express what the caregiver’s expressed to me as needs and wants to the client but not saying to much. I don’t know, it’s just really difficult sometimes.”*

*“No matter what you do for that caregiver, it affects [the care receiver]. If [the care receiver] does not want some strange woman sitting in the room with him for four hours, then he has the right to say no.”*

*“If the caregiver needs relief, two hours on Monday, and the client refuses... the consumer refuses that... there isn’t a way to force the issue..... if the consumer is their own guardian and signs their own release.”*

*“But we’ve always allowed the consumer the right to choose. And we’ve never been forceful about care and I think it would be an infringement on their rights.”*

*“I have a [PASSPORT] husband and wife and she’s had several strokes. She’s paralyzed on the right side. We went in to give personal care, to help with the home and she needs physical therapy and occupational therapy. When we went in, she accepted us. She said she wanted her husband to give her a bath because she feels more comfortable with his strength... that he can pick her out of the tub. I explained to her that the program that she’s in, the aid has to do the bath. She’s constantly saying that she wants the husband. Now the husband, behind her back, called the office and said he wants the service because he cannot do all... you know... do what she needs. But she is constantly wanting him to do it. So there is a conflict... You know, he’s sneaking behind her back to ask for the care.”*

Third, PASSPORT needs a uniform caregiver assessment process and management information system. It is clear that assessment and service plans are most

effective when they are person-centered. Individuals are capable of self-assessment; both caregivers and often care receivers can identify what they most need, what would achieve greatest relief, and what is “enough.”

The current PASSPORT assessment process and management information system should be modified to include assessment of caregiver need, reassessment of caregiver on a regular basis, community resources available to caregiver, management information on the number of caregivers served, and outcomes achieved. These modifications will help assure quality of care and measure caregiver outcomes. Also, modifying the assessment process to ensure caregivers have an opportunity to participate in service decisions will make a significant contribution to PASSPORT consumer’s health, welfare, and quality of life.

To accomplish the three proposed changes one of most important measures of success will be recognizing and supporting caregivers as legitimate consumers in long-term care and increasing the priority given to caregiver services. System change is difficult even with the strong leadership and support now evident at ODA. Without this leadership and support, system change will be impossible.

Real Choices: The final component to implementing PASSPORT respite is what we call “Real Choices.” In the April 2005 edition of Aging Connection (Ohio Department on Aging, 2005) Director Joan Lawrence was quoted as saying:

“Following the guidelines of Governor Taft’s Ohio Access initiative ([www.ohioaccess.ohio.gov](http://www.ohioaccess.ohio.gov)), Ohio’s Medicaid system will be consumer-directed, driven by clear choices and served by a competitive marketplace that offers a spectrum of services designed to meet the needs of the individuals served, not the system that serves them.

Ohio is now in the best position ever to balance its system of long-term care services and supports for seniors and people with disabilities. Expanding choice to families will improve our system by helping people make the best possible decisions for themselves, and it will encourage the health care marketplace to flourish as natural demand for services develops the real choices people want and need.”

We recommend this philosophy be applied to integrating “Real Choices” into ODA’s PASSPORT respite strategy. We learned from our focus groups that in order for respite to be effective it has to be responsive to unique individual needs, a conclusion supported by Reinhard, Bemis, and Huhtala (2005). PASSPORT is currently meeting

some individual needs with existing services. If the state allows for a broader conception of respite, its targets, types and beneficiaries, institutes a family-based approach to assessment, and modifies the PASSPORT system to support these changes it is likely that more traditional PASSPORT services will be utilized to support the caregiver and their loved one. But, PASSPORT will still fall short of meeting the unique individual needs of caregivers.

For example, take the recently cited case of a family that used National Family Caregiver Support Program (NFCSP) funds to pay for a car battery to make it possible to transport a relative to the doctor's office (Fienberg et. al., 2004). Fienberg *et al* (2004) continued by saying states are grappling with ways to improve quality and increase consumer choice – one way to accomplish this is by giving financial resources and choice to those that provide vital care to elderly and disabled relatives.

Our conceptual framework for understanding respite strategy suggests a highly complex mix of ADC strengths and ADC stresses. And, no two ADC arrangements are the same. We believe the solution to the problem, in addition to the system modification mentioned earlier, is adding flexibility and consumer direction.

A person-centered approach to reducing ADC Stress and increasing ADC Strength is not a matter of assessment only. It compels a flexible and wider array of service options and an option for consumer direction. It compels *real choices*. This is central to successful outcome.

Flexibility includes choice in who, what, when, where, why, and how of the ADC arrangement. Consumer direction allows families to control their Medicaid budgets and secure their own services. This program is founded on a person-centered approach. We know from experience with consumer direction in the State of Ohio that consumers who use it have better outcomes, including reduced risk of institutionalization (Kunkel & Nelson, 2005).

Two examples from *caregivers* suggest the impact of adding flexibility and consumer direction to PASSPORT.

*“You need a nurse to come in and check temperatures and check all this stuff cause see, my mother like uh....they left me there to learn how to stick her finger. I ... I cannot not stand to hurt my mom and she can't stand for me to [do it]. I come over there with this and I say mom, I got to take your [level] She says you're not going to stick me with that*



*thing. And I said it's just a....I'm just going to do it just a little bit. She said you're not going to do it."*

*"My dad's a diabetic and he has to have 3 shots a day and then his bedtime shot and then his medicine. ...If you had somebody coming in, you know, it would be nice to have.... to be able to have somebody that could do this and most of your aides, I don't think they're allowed...."*

One way to add flexibility and consumer direction to PASSPORT respite strategy is to add either a cash subsidy or voucher program that empowers caregivers to solve a problem unique to their own situation.

We call this "Real Choices." We see it as a modest, no-strings-attached cash benefit or voucher program that is grounded in a systematic assessment of the primary caregivers needs, similar to the flexibility built into the "supplemental services" part of the NFCSP program. Cash benefits to purchase goods and services will help offset the often higher cost of other services and/or for some enabling the caregiver to continue support of the care receiver.

Cash benefit programs are available in a number of states. Usually, they are supported through the "supplemental services" category of NFCSP. PASSPORT can learn helpful lessons from the experiences of NFCSP. NFCSP is speeding the adoption of more choice, more control, and more flexibility into the home and community-based system and evaluations to date indicate improvements in service quality, participant satisfaction, and supports and services which better meet consumer needs (Fienberg et. al., 2004). Since NFCSP and PASSPORT are administered by the same agency in Ohio, collaboration to educate PASSPORT service staff about the needs of caregivers will be easier than if the programs were isolated from each other.

We are proposing that ODA apply for a Medicaid waiver amendment to offer cash benefit/vouchers for "supplemental services" as part of the PASSPORT program. As far as we can tell there are only two other state waiver programs that use cash benefit/voucher programs: Alabama and Minnesota (Feinberg et. al. 2004). We believe our recommendation is consistent with CMS's Independence Plus initiative to promote self-direction. Further, results from the evaluations of programs using self-direction and individual budgets reveal a high degree of flexibility, improvements to service quality,

and enhanced participant satisfaction (Crisp et. al., 2003). More important, results from the evaluation of the cash and counseling demonstration projects indicate that higher Medicaid expenditures were offset by lower spending for nursing homes and other Medicaid services (Dale et. al., 2003).

We also acknowledge the financial and programmatic challenges of our recommendation. Real Choices will add costs to PASSPORT but our service plan cost and savings calculations demonstrate a modest investment in Ohio's respite strategy will save the state money.

When discussions are held about expanding options, concerns are often raised about a woodwork effect, that is, families coming out of the woodwork to claim benefits and services they might otherwise have done without. Participants in the *caregiver* focus groups shared perspectives that should allay some of these concerns.

*“The lady in charge of my husband’s PASSPORT program told me that there might come a time if I needed respite, you know, for a week or something ... so far I haven’t felt like I needed it.”*

*“At this point I believe I’m getting all the care that I need....[T]he first couple of years were the hardest. Up until maybe a year ago I started getting cabin fever and uh, my husband had always been real active and we always went on a lot of vacations and fishing trips so I started thinking I’ll never get to go on another vacation, but I wouldn’t want to go on one by myself so I got over that. I did take a little weekend.”*

Finally, we were concerned with the interface between consumer direction and cultural competence. Consequently, we used one focus group with PASSPORT professionals to pay particular attention to issues of racial and ethnic diversity in providing respite to the PASSPORT population. These urban area case managers had had training in cultural competence, but the training was occasional and somewhat superficial.

The need for a person-centered approach was made especially clear in this group. We maintain that a person-centered approach is inherently culturally sensitive because it allows for the expression of needs and preferences whether they are ethnically based, age based, gender based, and so forth. A person-centered approach to providing support

services gets straight to cultural needs and preferences because it gets straight to individual needs and preferences.

This is not to suggest that we can let go of our obligation to develop and practice cultural competence. Indeed, cultural differences may reveal themselves in the ways families negotiate services, among themselves, and with formal providers, even as a person-centered approach is used. And, cultural competence continues to be essential to the quality of service delivery.

### **HOW IT WOULD WORK**

We offer an extension of the Karen and Arla example to better understand the impact of the proposed PASSPORT Respite Strategy on PASSPORT caregivers and care recipients. Flexibility includes choice in who, what, when, where, why, and how of the ADC arrangement. In the case of Karen and Arla, care is most successfully kept at home when person-centered, meaningful changes are made in the who, what, where, when, how, and why of the ADC arrangement, sufficient to reduce ADC Stress. Real Choices are necessary to achieve the most successful outcome possible.

**Karen and Arla: An Alternative Positive Outcome  
(Hypothetical Scenario)  
Example and Figure 3**

A successful outcome is achievable in multiple ways. Although adult day service made a dramatic difference in the lives of Karen and Arla, other changes in the ADC arrangement might have been as successful. Services to increase ADC Strength would also help.

**Reducing ADC Stress**

**The following interventions to change the ADC arrangement represent a respite strategy.**

A monitoring system and door alarms are installed to reduce Arla's need for supervision, effectively increasing her self care.

A few of Karen's less reluctant siblings are included in a family assessment to negotiate greater cooperation. A written instrument is used to inspire ways to help and to develop a sense of contract among siblings.

Ruth, one of Mary's sisters, decides to stay with Arla on Fridays. One of Mary's brothers agrees to take Arla to dinner on Wednesday nights while Karen attends a support group.

One of Karen's sisters recently lost her job. Using consumer direction, Karen hires her to stay with Arla on weekends to allow Karen time to study.

Arla goes to adult day service 4 days a week instead of five.

Finally, Arla receives brief institutional care for one week each year, so that Karen and her son can have a vacation.

Karen is more rested and less anxious at home. Karen feels less isolated and less angry at her siblings. Family relationships are improved and Arla is reconnected to some of her children.

**Increasing ADC Strength  
Other Support Services are provided.**

Karen says, *"But if someone could have been there to just gradually just come in and help me get used to, you know, what was going on, I think it would have been better for everybody involved. I wouldn't have been so reluctant and aggravated and upset all the time."*

Karen receives in-home counseling to learn coping techniques.

Karen attends a weekly support group of younger caregivers. The group fortifies Karen and sustains her through each week.

Karen and her sister Ruth attend caregiver education groups at the Alzheimer's Association. They have a better understanding of dementia. They learn communication, behavior management, and coping skills.

Karen is connected to the National Family Caregiver Support Program coordinator who provides information and referral services.

Outcome:

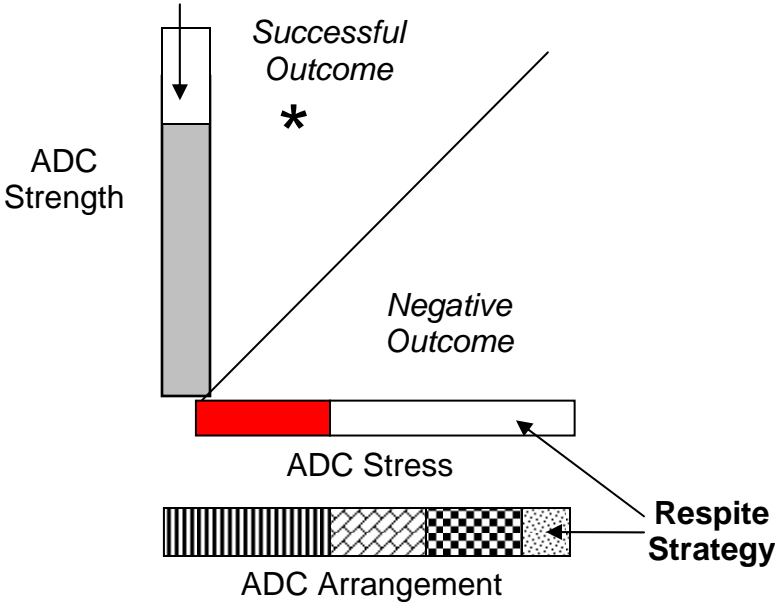
- ADC Stress is reduced by interventions in the ADC arrangement (technology to increase self care, methods to increase informal respite, brief use of institutional respite, and reduction in the use of HCBS)
- The nature and level of Karen's ADCs are meaningfully changed to reduce ADC Stress.
- Karen's ADC Strength is increased by the use of Other Support Services.
- Her ADC Stress no longer exceeds her ADC Strength.
- Physical and emotional health are preserved.
- Quality of life is improved for both Karen and Arla.
- Family relationships are improved.
- Successful care at home is maintained.

# Figure 3

## Successful Care at Home: A Support Model (An Alternative Successful Outcome)

Karen and Arla

**Other Support Services**



- Caregiver
- Informal Respite
- I/HCBS
- Self Care

## **SUMMARY AND CONCLUSION**

Our work under the “Adult Respite Feasibility Study Project” was to define the scope of respite and to develop an implementation plan. Respite is a strategy that is both a service and an outcome. Respite is an important tool to keep care at home (and out of the nursing home), for as long as possible and appropriate, while maintaining optimal health and quality of life of both caregivers and care receivers, and while containing family and public costs.

In order to better understand the complexities of respite strategy, we created “Successful Care at Home: A Support Model” to help case managers assess and plan for PASSPORT services. This new model is untested, but we believe that conceptually the model provides indications for a respite strategy and other support services provided in PASSPORT service plans.

Next, we developed a profile of caregivers and a model, that includes estimates the potential number of future PASSPORT consumers, to determine the financial impact of possible respite interventions. We feel any PASSPORT intervention that helps the caregiver will generate potential savings in the long run.

Finally, we outlined a four component family-based PASSPORT respite strategy starting from PASSPORT in its existing state to adding flexibility and consumer direction in the form of a cash benefit or voucher program. Step by step execution of the each component of the proposed respite strategy will take PASSPORT from where it is today to where we believe it should be in the future.

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