

Elderly Caregivers of Adults with Disabilities Pilot Project Evaluation

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Introduction

The Institute on Disabilities at Temple University was contracted by the Pennsylvania Department of Aging (PDA) to evaluate the Elder Caregiver of Adults with Disabilities Pilot Project. This project, funded by a grant from the United States Administration on Aging, was piloted in Allegheny and Montgomery Counties. The project was designed to provide support to primary caregivers, over the age of 60, caring for their adult relatives with disabilities. Through collaboration with the county Area Agency on Aging Family Caregiver Support Project Coordinators, caregivers and care-managers, the Institute on Disabilities collected the data necessary to evaluate the project. This document reports the results of the final round of data collection.

Since the start of the project in 2002, data had been collected on potential participants through the use of a referral form, developed by the Institute on Disabilities in collaboration with the Pennsylvania Department on Aging. The Allegheny County and Montgomery County Area Agencies on Aging sent the Institute on Disabilities the referral forms upon completion. The agencies also provided researchers with information regarding which applicants were accepted into the program, as well as information as to who was declined enrollment or dropped out and why.

A survey instrument was designed to evaluate the project. The survey consisted of seven sections. The sections included: information about the family, supports the family received, satisfaction, accessibility and flexibility, choice and control, how much life had changed and comments. The survey was used by the researchers in conducting face-to-face interviews with the caregivers enrolled in the project.

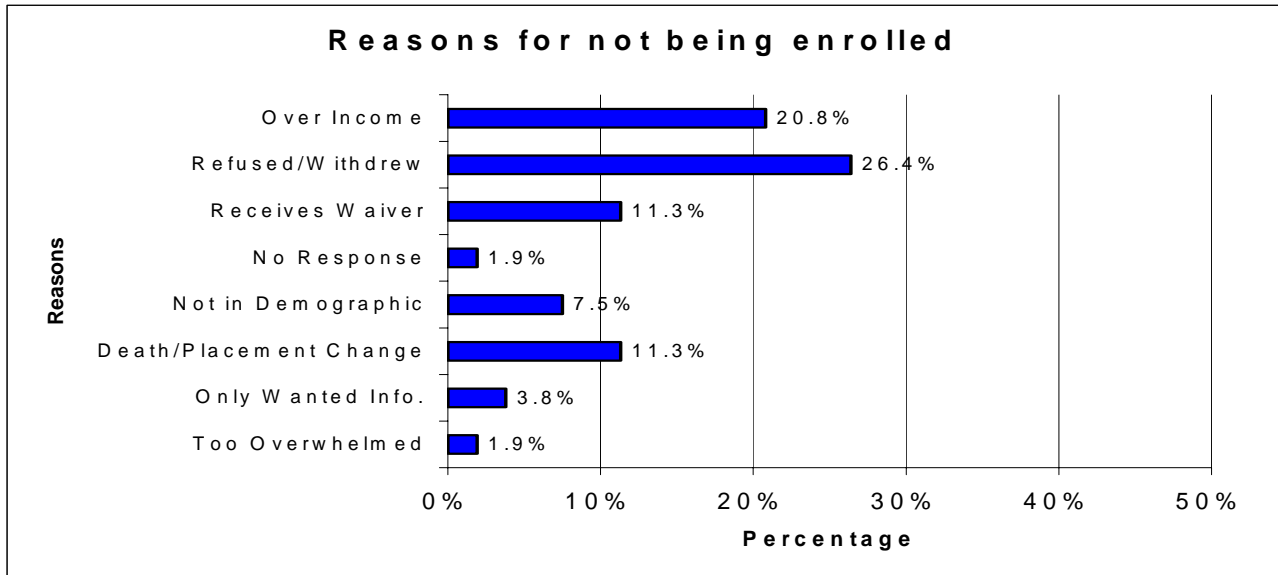
This report is divided into seven sections. The first two sections provide information regarding participation as well as general demographic and need information obtained from the referrals. The next section reports the service and support-related data compiled from all the interviews that were completed in the summer of 2004. Evaluative data reflecting the perspectives of those who were new to the program as of December 2003 and were only interviewed once can be found in the next section. Also found in the report is a comparison of initial interviews and post interviews of those individuals who were interviewed twice after their initial referral to the program. The end of the report provides a summary of the remarks provided by project staff and general observations of the interviewer.

Participation

As of the end of August 2004, 103 referrals from individuals wanting to participate in the Elderly Caregivers of Adults with Disabilities Pilot Project had been received. Montgomery County received 47 referrals and Allegheny County received 56. There were 48 caregivers enrolled in the project, 26 from Montgomery County and 22 from Allegheny County. There was one referral being assessed for possible enrollment and one caregiver was on a waiting list due to budget constraints.

Of the 103 referrals, 53 caregivers were not enrolled in the project for a variety of reasons.

- 11 of the caregivers were over the income limit
- 14 refused services or withdrew their application
- 6 were receiving waiver services and were therefore ineligible to participate in the project
- 1 did not respond following the initial contact
- 4 did not meet demographic requirements (county, age, disability)
- 6 were no longer enrolled due to the death of the caregiver or a change in the placement of the care-receiver
- 2 requested information only
- 1 of the caregivers was too overwhelmed and declined participation
- 1 withdrew from program due to care-receiver turning 60 and therefore eligible for other services
- 2 withdrew due to failure to use services
- The 5 remaining individuals referred to the program were not enrolled for a variety of other reasons.



Referral Information

The information listed in this section was compiled from the referrals completed by the Montgomery County and Allegheny County Area Agencies on Aging and sent to the Institute on Disabilities.

Demographics

Most of the caregivers referred to the project were between the ages of 66 and 75 at the time of referral. The mean age was 72 years.

- 19 of those referred were between the ages of 60 and 65
- 24 were between the ages of 66 and 70
- 22 were between the ages of 71 and 75
- 18 were between the ages of 76 and 80
- 9 were between the ages of 81 and 85
- There was one caregiver between the ages of 86 and 90 and one older than 91 years of age.
- 9 individuals did not share their ages with the interviewer

Of these caregivers, a large majority (73.5%) were maternally related to the adult with a disability for whom they care. Fathers accounted for 17.6%. The remaining individuals were either grandparents, siblings, aunts or another relative.

Approximately half of the referred caregivers' households consisted of themselves and the individual for whom they care. Forty-three percent of the caregivers lived in households consisting of three individuals; typically the residents included the primary caregiver, spouse and adult child with a disability.

There was great variability in the age ranges of the individuals being cared for by the caregiver. The mean age was 41 years.

- 4 of the care-receivers were between the ages of 18 and 25 at the time of referral
- 5 were between the ages of 26 and 30
- 19 were between the ages of 31 and 35
- 22 were between the ages of 36 and 40
- 24 were between the ages of 41 and 45
- 12 were between the ages of 46 and 50
- 17 were older than 51 years of age

There was some variation in the reported range of income levels for those referred to the Elder Caregiver Project. Approximately 70% of those referred reported a family income between \$10,000 and \$30,000 per year.

- 1.2% of caregivers referred reported a family income of less than \$10,000 per year
- 25.9% reported a family income between \$10,000 and \$20,000 per year
- 43.5% reported a family income between \$20,001 and \$30,000 per year
- 18.8% reported a family income between \$30,001 and \$40,000 per year
- The remaining caregivers referred to the program reported an income level of greater than \$40,000

Request for Supports

The referral forms presented to the Area Agencies on Aging included information regarding the supports and services the caregivers needed to help them take care of their family member with a disability. Some of the services needed most by the caregivers (ranked from most requested to least requested) included:

- Respite care (25%)
- Homemaker services (19.3%)

- Home renovation/modification (18.2%)
- Medical expenses/health related items (18.2%)
- General household expenses (food, supplies, heating, clothes)(18.2%).

Some of the other services reported as needed included: transportation services, therapy, home nursing care, diapers, recreation, care management, health insurance and/or car/van modification/repair.

Interview Information

The following data were received from information obtained from individuals enrolled in the project and interviewed by staff from the Institute on Disabilities. Unless otherwise noted, there was no significant difference in the comparison data between the two counties.

As of June 2004, there was a total of 48 caregivers enrolled in the Elder Caregiver of Adults with Disabilities Pilot Project. Twenty-two resided in Allegheny County and 26 lived in Montgomery County. Twenty-four second interviews and 13 initial interviews were completed in the summer of 2004. Seventeen of the Allegheny County caregivers and 20 of the Montgomery County caregivers were interviewed. The remaining individuals had not been interviewed for the following reasons:

- 2 caregivers (Montgomery Co.) entered the program in May 2004 or more recently; this made it too early to interview them
- 5 caregivers (4 Allegheny Co./1Montgomery Co.) refused to participate in the interview
- Consent was never received from one individual
- There were ongoing scheduling difficulties with the remaining 3 individuals that needed to be interviewed.

Information about the Families

A majority of the pilot project participants were mothers caring for their adult children (83.8%). Information from the interviews revealed that over half of the adults with disabilities were female (67.6%). Many of the households (64.9%) consisted of a single parent caring for their adult child. Approximately 33% of the households enrolled in the project had two parents living in the home.

During the interview the caregivers were asked questions regarding the assistance needed by the care-receiver in order to complete a variety of activities.

- 48.6% of individuals with disabilities needed at least some assistance toileting
- 48.6% needed at least some assistance eating
- 70.2% needed at least some assistance bathing
- 56.7% needed at least some assistance dressing
- 59.4% needed at least some assistance grooming
- 48.6% needed at least some assistance communicating
- 86.5%, according to the caregivers, needed at least some assistance making decisions
- 78.3% needed at least some assistance when learning new things
- 43.2% needed a least some assistance moving from place to place
- 100%needed assistance with transportation

Supports and Services

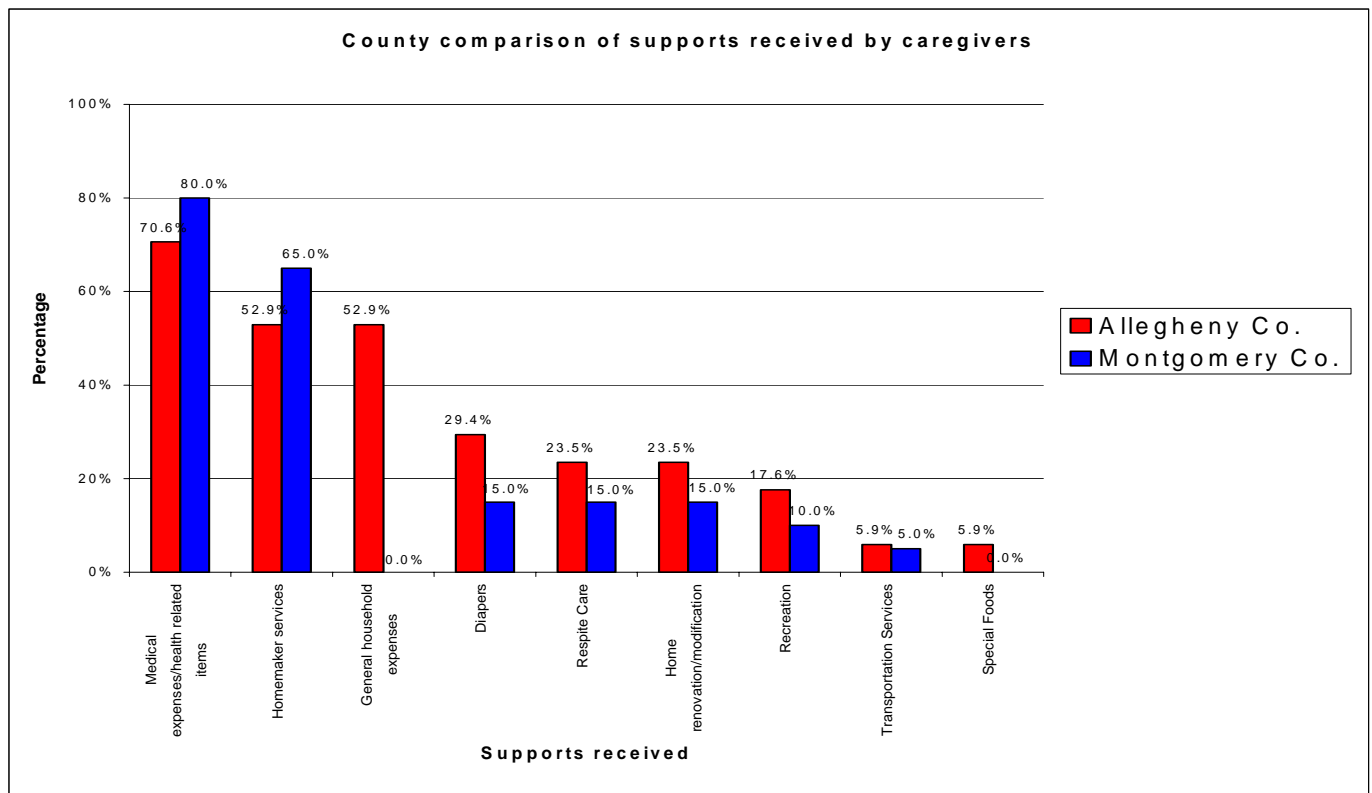
The caregivers provided information, during the interview process, regarding the supports and services they were receiving as a result of support received through the Elder Caregiver Project. The caregivers utilized a wide variety of supports and services. As reported by the caregivers, some of the support received included:

- care management (75.7%)
- a family/caregiver needs assessment (91.9%)
- information services (62.2%)
- family consultation/care planning (56.8%)
- referral services (29.7%)

The caregivers also reported that they received reimbursement for a variety of services and products. These included:

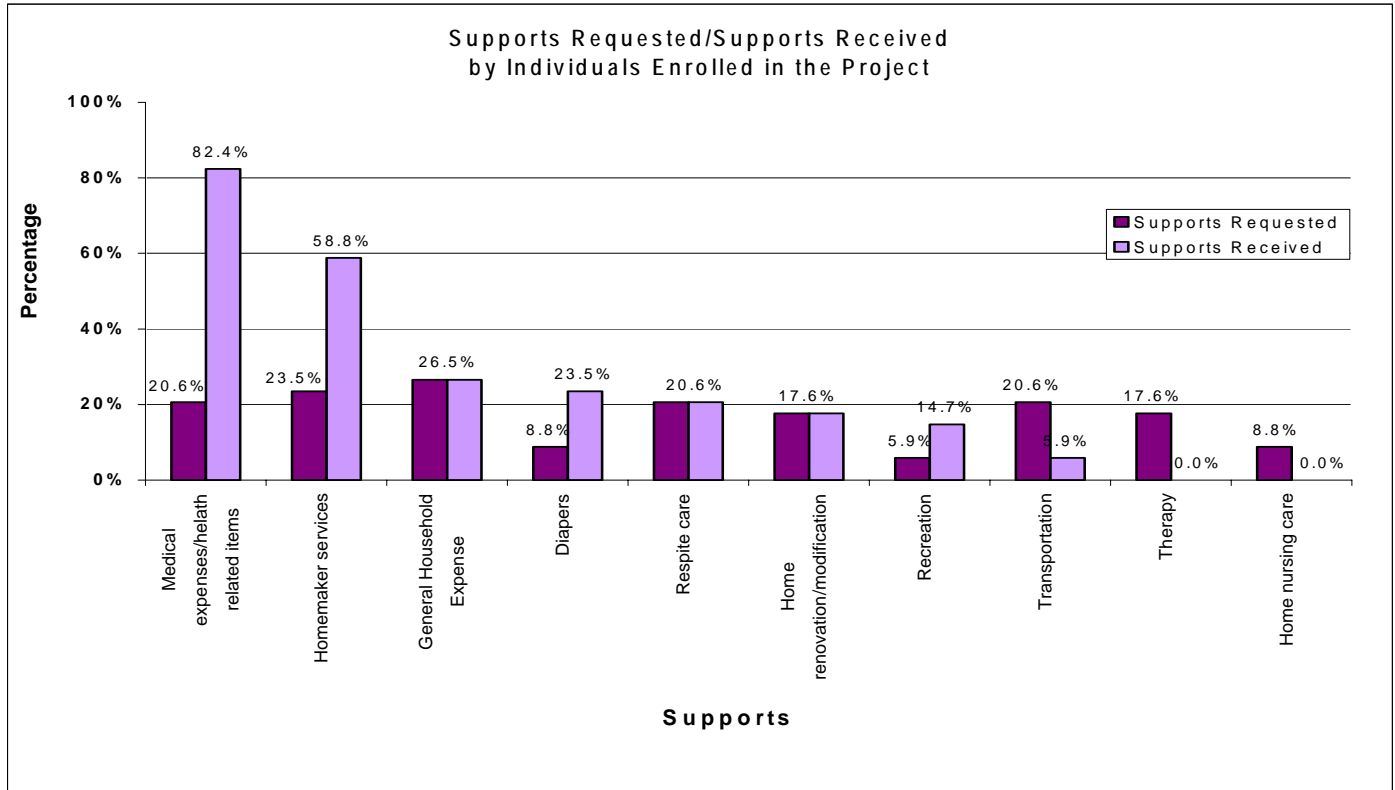
- medical expenses/health related items (75.7%)
- homemaker services (59.5%)
- general household expenses (food, supplies, heating, clothes) (24.3%)
- diapers (21.6%)
- respite care (18.9%)
- home renovation/modification (18.9%)
- recreation (13.5%)
- 18.9% of the caregivers received a variety of other services not listed in the survey such as special furniture, appliances, and home maintenance beyond homemaker services.
- A small percentage of respondents received reimbursement for special foods (2.7%), adaptive equipment (8.1%) and transportation (5.4%)

Below is a chart comparing the services received by project participants in each of the counties.



* Please note that the numbers do not add up to 100%, as caregivers may have received multiple supports

Below is a chart comparing the percentage of supports requested during the referral process by the caregivers enrolled in the project and the percentage of supports these caregivers received as a result of the project:



Only 24.3% of caregivers enrolled in the program reported having a support or service they requested denied. The items that were denied included hearing aid batteries, painting of a house, repairs to a Florida room, retroactive payment on yard work, having a tree cut down, paving of a sidewalk with a new railing and transportation through ACCESS.

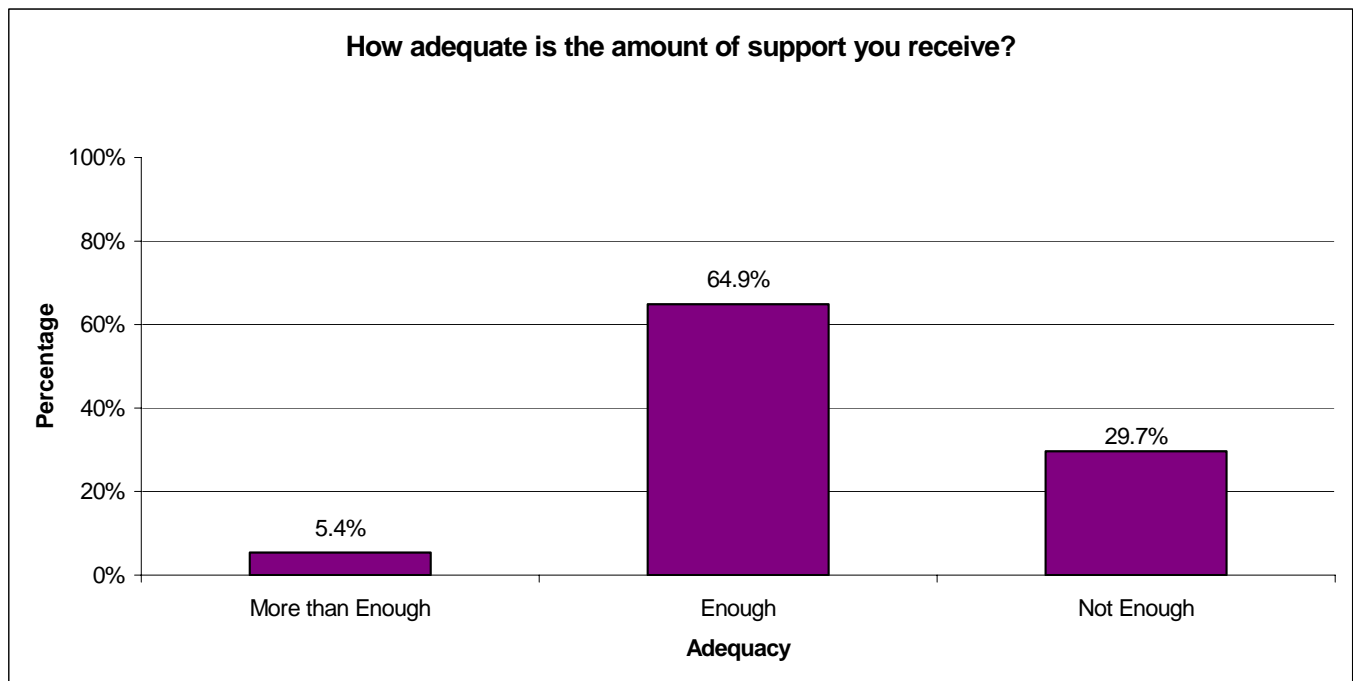
Many of the families reported that they received support from programs other than the Elder Caregiver Project. The additional support received most frequently by the caregivers in this project was Medicaid Medical. The following lists the four most frequently received supports and/or services and the percentage of interview respondents that received each:

- Medicaid Medical (83.8%)
- Medicare (81.1%)
- Support Coordination (67.6%)
- Adult Day Services (48.6%)

Of the caregivers interviewed, 18.9% supported their family members with disabilities without other assistance. Thirty-two percent provided support for their family member with the help of paid professional help. In addition to the supports and services the families received through the state and various providers, many received assistance from friends, family and neighbors.

- 29.7% supported their family member with a disability with the help of a family member living inside the home
- 37.8% received assistance from relatives living outside the home
- 18.9% received assistance from friends
- 13.5% received help from neighbors
- A small percentage of respondents received assistance from other families with disabilities and religious worship members (2.7% each)

When the caregivers were asked a question regarding the adequacy of all the support/services they received, through the Elder Caregiver Project as well as other programs and providers, many stated that they received enough support (64.9%). Of the caregivers interviewed, 29.7% stated that the support they received was not enough to help them care for their family member. Only 5.4% stated that the support they received was more than enough.



Initial Interview with New Participants

The following data reflect the responses provided by those individuals who started participating in the program after December 2003. Due to their recent enrollment in the program these individuals were only interviewed once.

Satisfaction

During the evaluation process, the 13 newly enrolled caregivers were interviewed once since their enrollment in the program. These individuals were asked a variety of questions regarding their satisfaction with the support/services they received. The responses could have included **not satisfied at all, a little satisfied, moderately satisfied, very satisfied, extremely satisfied or not applicable.**

- Many respondents reported being extremely satisfied (53.8%) with the way they were treated by the people involved with the family support program. The remaining individuals were very satisfied.
- 61.6% of the caregivers reported being at least very satisfied with the information they received about the family support project
- 84.6% were at least very satisfied with the process used to decide which families would be selected to receive support
- 58.3% were at least very satisfied with the amount of support they received from the project
- 81.8% were at least very satisfied with how quickly reimbursement was received
- 69.3% were at least very satisfied with the amount of paper work they were asked to complete or provide

Note on Satisfaction Research

Although these percentages indicate a high level of satisfaction, this type of research usually yields high satisfaction rates. Individuals who receive supports and services tend to appreciate getting such services and therefore see themselves as satisfied. Moreover, people with limited options may not have the experience to know that services could be better.

Accessibility and Flexibility

The interviewed caregivers were asked many questions regarding their experience with getting into the program and its flexibility. The responses for each question could have been **never, sometimes, always or don't know**.

- Many of the caregivers (92.3%) did not know if the program was advertised in different languages and in different ways so that their family could easily find out about it
- Most caregivers (61.5%) thought the application and planning processes were always sensitive to their cultural needs and preferences
- 92.3% of the respondents thought that the application process was always friendly, quick and without a lot of personal and irrelevant questions
- Regarding information provided in order to describe the program in terms of its philosophy, mission and operations (what could be expected), only 46.2% stated that adequate information was always provided
- 23.1% responded that supports were always available when their family wanted and needed them; 46.2% stated that they didn't know because they never asked for additional supports
- 53.8% stated that supports were always provided for his/her entire family
- For a majority of the caregivers (76.9%), the person that coordinated his/her support services was always available when they wanted

Choice and Control

This section of the survey focused on the amount of choice and control the caregivers had over the supports and services they received. The questions focused on the program, its staff and the outside resources it may or may not have utilized. The responses that could have been given were **always, usually, sometimes, rarely, never or don't know**.

- Only 30.8% of the caregivers reported that program staff always provided the family with information so they could see all the options available to the family member with a disability and to other family members
- All of the respondents stated that the services and supports were always provided in ways that respected their confidentiality
- Many of the caregivers (92.3%) did not know if the program used local resources available through the private sector such as employers and local recreation centers or senior centers

- Some respondents (38.5%) stated that the program always used informal networks such as friends and neighbors; 53.8% did not know if these resources were utilized.
- All of those surveyed stated that program staff was always honest with them.

The following responses for the control questions were answered using a response of **none, a little, some, a lot or complete**.

- 53.9% of the respondents stated that they had at least a lot of control over the supports their families received through the Elderly Caregiver Project.
- Less than a quarter (23.1%) of the caregivers surveyed stated that they had at least a lot of control over the supports received from programs outside of this project.

Therefore, people felt that they had more control over program services than other supports and services.

How Life Has Changed

In this section of the survey the caregivers responded to a number of questions focused on how the Elder Caregiver Project had changed their lives. Those interviewed responded to the questions by stating whether their lives had changed in a particular area **for the worse, for the better or hadn't changed at all** as a result of the program.

- 61.5% of the interviewed caregivers stated that the overall lives of their families had changed for the better.
- Many respondents (92.3%) reported no change in their families' ability to do more together
- 46.2% reported a change for the better with regard to the stress in their families' lives; the remaining individuals reported no change
- 38.5% of the caregivers interviewed stated that as a result of the program their ability to care for their family members had changed for the better; 61.5% did not think there was any change
- 92.3% saw no change in their worries about their family members' future and well-being
- 53.8% stated that their ability to do things they were unable to do before changed for the better
- Most caregivers (92.3%) saw no change in their ability to get to know other people in their communities; the same percentage of caregivers also saw no change in their family members' level of inclusion in the community

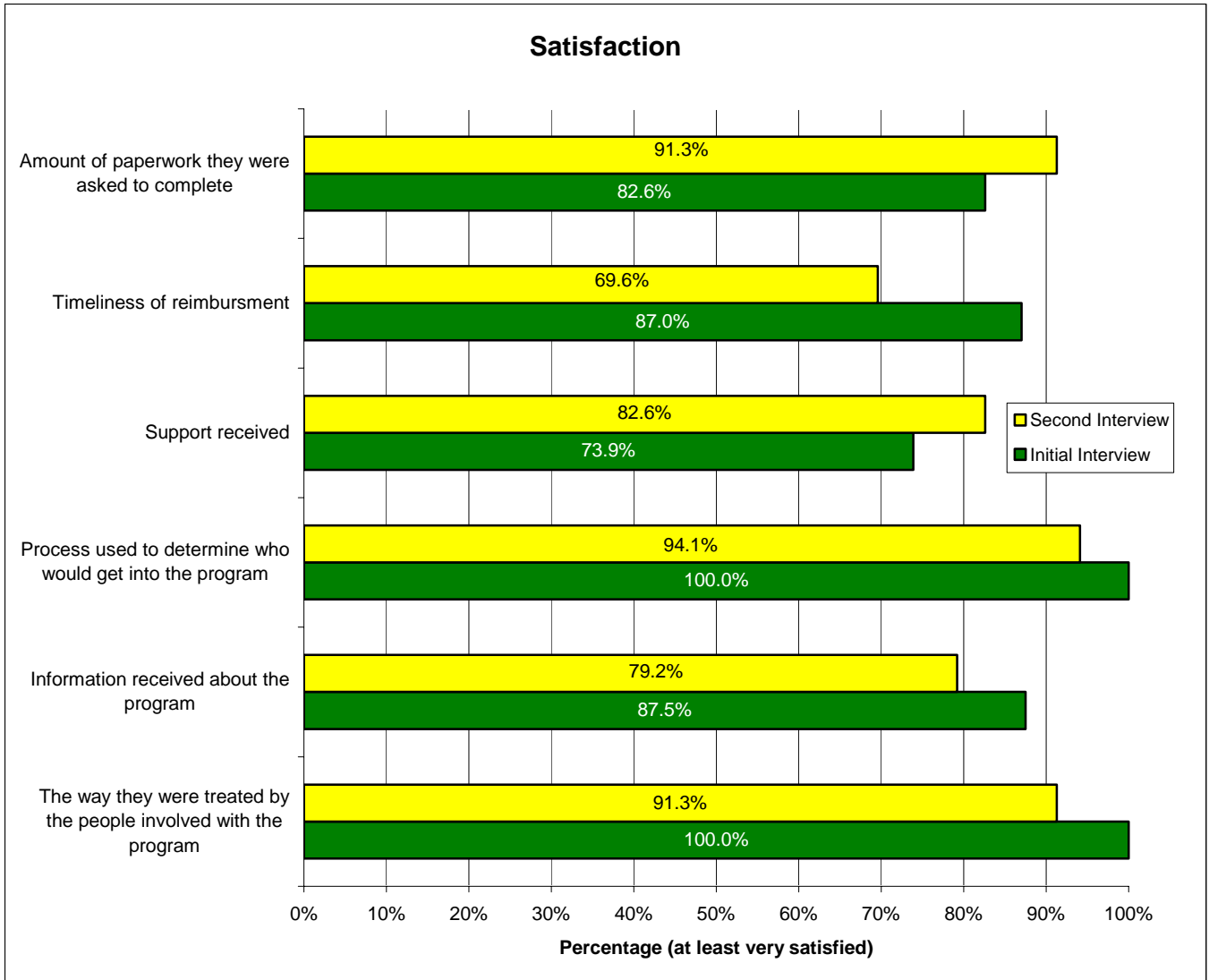
Comparison Between First and Second Post-test Interviews

Twenty-four caregivers were interviewed twice while they were participating in the program. A comparison was made between their initial interview responses and the responses that were given during the second interview. The information found below reflects the results of the second interview with the initial interview data found in parentheses.

Satisfaction

During the evaluation process, there were 24 caregivers that were interviewed twice. These individuals were asked a variety of questions regarding their satisfaction with the support/services they received. The responses could have included **not satisfied at all, a little satisfied, moderately satisfied, very satisfied, extremely satisfied or not applicable.**

- 91.3% were at least very satisfied with the amount of paper work they were asked to complete or provide (82.6% initial interview)
- 69.6% were at least very satisfied with how quickly reimbursement was received (87% initial interview)
- 82.6% were at least very satisfied with the amount of support they received from the project (73.9% initial interview)
- 94.1% were at least very satisfied with the process used to decide which families would be selected to receive support (100% initial interview); one individual reported being only moderately satisfied
- 79.2% of the caregivers reported being at least very satisfied with the information they received about the family support project (87.5% initial interviews)
- 91.3% reported being at least very satisfied with the way they were treated by the people involved with the family support program (100% initial interviews); two individuals were only moderately satisfied

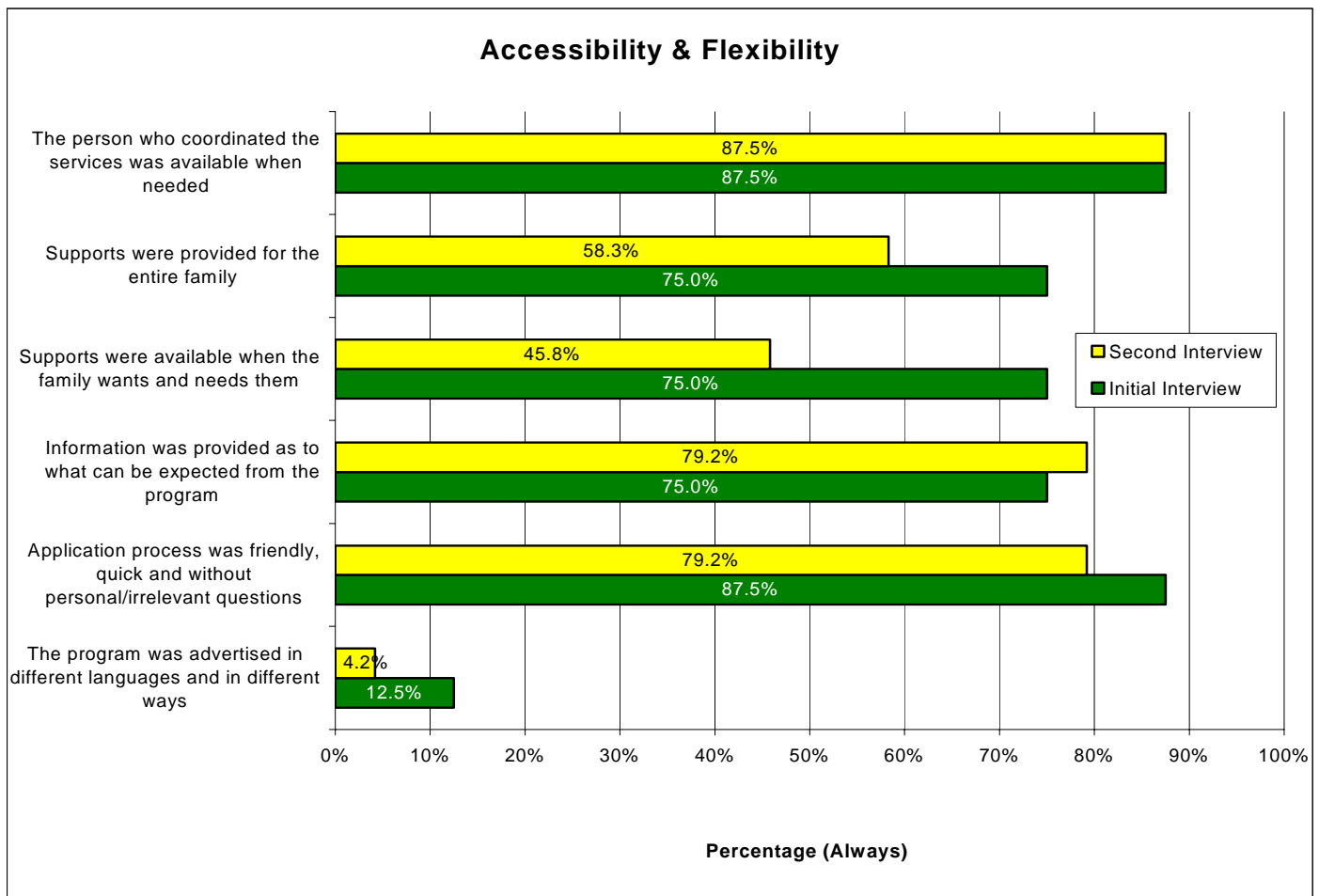


Accessibility and Flexibility

The interviewed caregivers were asked many questions regarding their experience with getting into the program and its flexibility. The responses for each question could have been **never, sometimes, always or don't know**.

- For 87.5% of the caregivers, the person that coordinated his/her support services was always available when they wanted (87.5% initial interviews)
- 58.3% stated that supports were always provided for his/her entire family (75% initial interviews)
- 45.8% responded that supports were always available when their family wanted and needed them (75% initial interviews); 33.3% didn't know because they didn't ask for any additional supports (16.7% initial interviews)

- Regarding information provided in order to describe the program in terms of its philosophy, mission and operations (what could be expected), 79.2% stated that adequate information was always provided (75% initial interviews)
- 79.2% of the respondents thought that the application process was always friendly, quick and without a lot of personal and irrelevant questions (87.5% initial interviews)
- 79.2% did not know if the program was advertised in different languages and in different ways so that their family could easily find out about it (75% initial interviews)



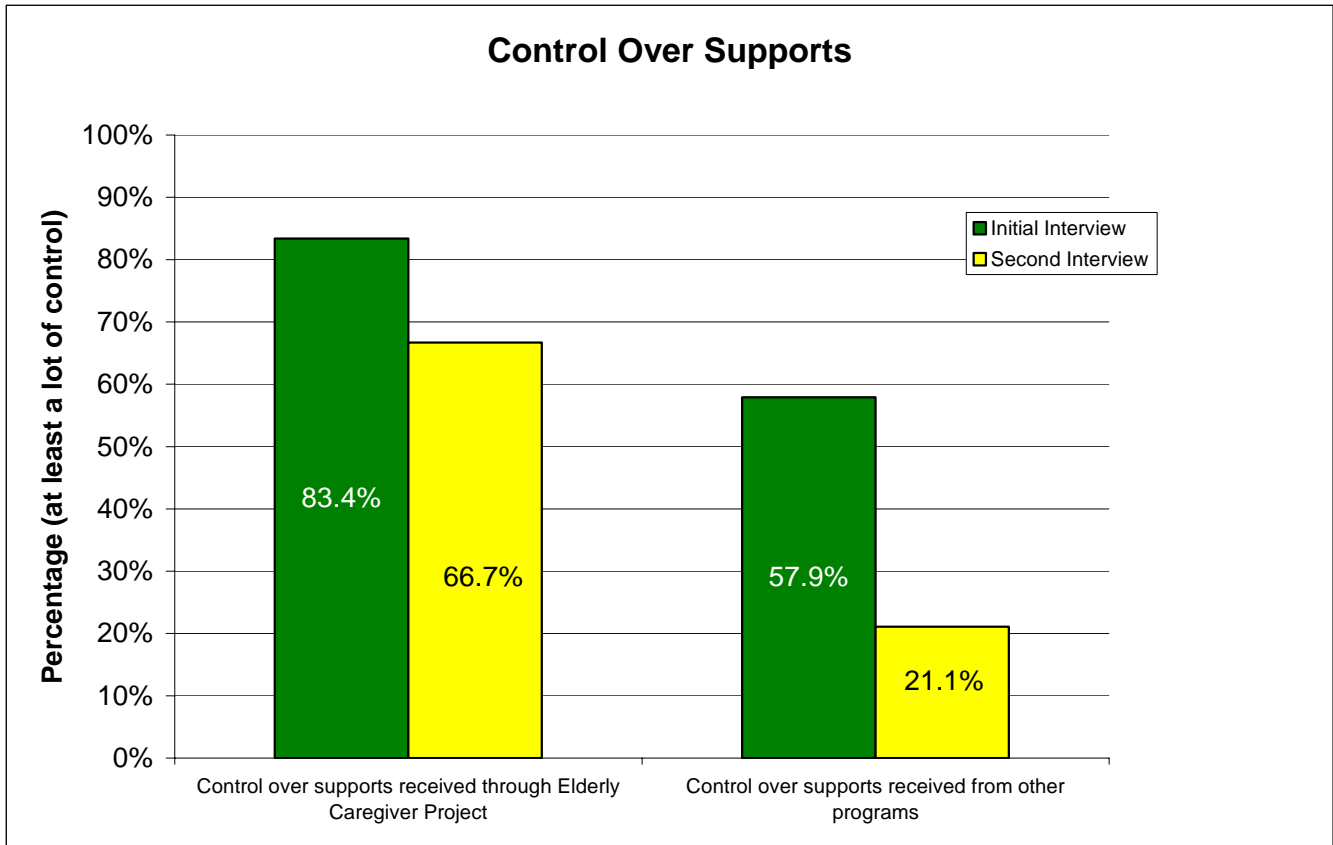
Choice and Control

This section of the survey focused on the amount of choice and control the caregivers had over the supports and services they received. The questions focused on the program, its staff and the outside resources it may or may not have utilized. The responses that could have been given were **always, usually, sometimes, rarely, never or don't know**.

- Only 33.3% of the caregivers reported that program staff always provided the family with information so they could see all the options available to the family member with a disability and to other family members (50% initial interviews)
- 91.7% of the respondents stated that the services and supports were always provided in ways that respected their confidentiality (91.7% initial interviews)
- 87.5% of the caregivers did not know if the program used local resources available through the private sector such as employers and local recreation centers or senior centers (66.7% initial interviews)
- 29.2% stated that the program always used informal networks such as friends and neighbors (37.5% initial interviews); 62.5% did not know if these resources were utilized (41.7% initial interviews)
- 95.8% of those interviewed stated that program staff was always honest with them (91.7% initial interviews)

The following responses for the control questions were answered using a response of **none, a little, some, a lot or complete**.

- 66.7% of the respondents stated that they had at least a lot of control over the supports their families received through the Elderly Caregiver Project (83.4% initial interviews).
- Less than a quarter (21.1%) of the caregivers surveyed stated that they had at least a lot of control over the supports received from programs outside of this project (57.9% initial interviews).



How Life Has Changed

In this section of the survey the caregivers responded to a number of questions focused on how the Elderly Caregiver Project had changed their lives. Those interviewed responded to the questions by stating whether their lives had changed in a particular area **for the worse, for the better or hadn't changed at all** as a result of the program.

- 73.9% of the interviewed caregivers stated that the overall lives of their families had changed for the better (78.3% initial interviews).
- 73.9% reported no change in their families' ability to do more together (69.6% initial interviews)
- 60.9% reported a change for the better with regard to the stress in their families' lives (60.9% initial interviews)
- 59.1% of the caregivers interviewed stated that as a result of the program their ability to care for their family members had changed for the better (50% initial interviews)
- 61.9% saw no change in their worries about their family members' future and well-being (61.9% initial interviews)

- 56.5% stated that their ability to do things they were unable to do before changed for the better (52.2% initial interview)
- All of the caregivers saw no change in their ability to get to know other people in their communities (95.7% initial interviews); the same percentage of caregivers also saw no change in their family members' level of inclusion in the community

Summary

This report presents information collected through 103 referrals and 72 interviews with caregivers of adults with disabilities, program coordinators, care managers and an agency involved as a referral source for the Elder Caregiver of Adults with Disabilities Project. The referrals indicated a need for support and services for adult caregivers. This demand will most likely continue, especially as the number of aging parents caring for their adult children with disabilities in their own homes increases. This pilot project began the process of providing supports and services to some of these families.

The evaluation yielded positive results in terms of the supports provided to the caregivers. More than half of the caregivers reported that the supports and services provided by the program were meeting their needs. The interviewed caregivers also reported high levels of satisfaction with the program. They were particularly satisfied with the way they were treated by the people involved with the project. The caregivers also reported high levels of choice and control over the supports and services they received through this project.

The comparison of initial interviews and second interviews showed some decreases in satisfaction as well as in the areas of perceptions of accessibility and flexibility. Most notably, fewer caregivers stated, during the second interview, that supports were available when their family wants and needs them. Fewer caregivers also responded that supports were provided for the entire family.

Regarding choice and control more caregivers gave a response of “don't know” in the second interview than in the initial interview. The Allegheny County participants knew that the program was ending prior to participating in the post interview; this could have contributed to greater negativity and/or honesty when discussing their satisfaction. They were also more likely to share information regarding their lack of knowledge as to the goals of the project and the supports provided.

Overall, caregivers believed that they had more control over the supports they receive from this program than the supports they receive from other programs. In comparing the second interview to the first interview more caregivers reported having less control over supports received from other programs. After being enrolled in this program for an extended period of time, the caregivers may have been better able to compare the control they have over supports and provide a more accurate response.

The responses given by the caregivers in regard to how the program changed their families' lives remained stable over time. Most of the caregivers reported that the program had changed their families' lives for the better in terms of their level of stress, ability to care for their family member and their ability to do things they were unable to do before. With regard to community inclusion and worries about the future, a majority of the caregivers saw no change. This is not surprising, in that the supports provided through this pilot program do not necessarily assist families in planning for the future.

Many caregivers stated that the program gave them a "peace of mind" they didn't have before. Most caregivers reported that they received enough support and were appreciative of the reimbursement and support they had received. However, many were able to think of additional support they could use. Some of their ideas included: more respite, additional help around the home (handy-man, cleaning, painting, etc.), transportation, recreation for the family member, household items, etc. Most of the caregivers suggested that they would like to have a list available showing them the options they have for support.

The caregivers had some suggestions as to how they would improve the program. Most stated that the program should be advertised better because there are many families like theirs that could use services. The caregivers often commented that there needs to be more money out there to help families caring for their adult children with disabilities. The caregivers, particularly those in Allegheny County requested that the program be continued.

Many stated that they would have liked to have been informed about all the services and supports that could be reimbursed. This was not done, we assume intentionally, so as not to constrain the choices of supports made by families. Others would have liked to have services provided by the agency itself, instead of them having to look for people to provide the service. Some stated that direct payment to individuals providing services would be preferred over reimbursement.

Although the structure of the Elderly Caregiver Project needs to be refined in order to be more successful, it has provided much needed support to caregivers in Montgomery and Allegheny Counties. It has made many of these caregivers more aware that there are programs out there to help them care for their adult children and perhaps more importantly, it made many of them start thinking about the future. Programs such as this are necessary, especially as more and more adults with disabilities choose to live in the community with their families. Options need to be available for these families in order for them to be able to continue to care for their adult children and maintain satisfactory lifestyles themselves. Continued collaboration between aging agencies and disability agencies needs to occur if new and improved programs are to be designed and utilized to their fullest potential.

Program Staff Interviews

This section summarizes the responses given during the interviews completed with eight individuals involved with the Elderly Caregiver Project. Both of the program coordinators from the two counties were interviewed. Seven care managers (5 in Allegheny County, 1 in Montgomery County) and the chief executive officer of United Cerebral Palsy of Pittsburgh (UCP) were also interviewed.

Recruitment and Retention

Although there were some similarities, recruitment methods varied between the two counties. The Allegheny County program held two information sessions with the assistance of UCP. Many county agencies were invited to these sessions. The first session was unsuccessful in terms of attendance. The second session was reported as having more agencies participating. The sessions were designed to promote recruitment; however, some of the supports coordinators in attendance reported that they thought of it as “another training session” and not an event that persuaded them to go and recruit participants. The links made to developmental disability organizations during the UCP sessions did result in a majority of the referrals, but the numbers were still lower than expected.

The Allegheny County Area Agency on Aging also made contacts with the county mental health/mental retardation office, presented at many support coordinator meetings and placed an advertisement in Aging News. It was approximated that 28% of the referrals came from county MR supports coordinators.

Allegheny County filtered out caregivers receiving waiver services making them ineligible to participate. Although this was a logical decision as waiver recipients should be receiving supports to meet all of their stated needs, this decreased the number of individuals who could participate. It was also noted that the untimely death of the original coordinator and the time gap before appointing a new one led to a loss of momentum for the project.

Montgomery County used similar methods of recruitment. They reported that recruitment got off to a slow start, but eventually started to speed up toward the end of the pilot project. The program coordinator for the pilot project contacted the Montgomery County office of Mental Health/Mental Retardation (MH/MR). This avenue was not successful, reportedly due to turnover in staff and failure of MH/MR to distribute flyers and other program information until many follow-up contacts were made.

The Montgomery County Area Agency on Aging did a number of mass mailings to area churches, doctors' offices, agencies, and locations found in the county office telephone directory. Although it was reported that follow-up was done, those contacted did not provide much assistance with the recruitment effort. Information was also provided to Resources for Human Development, a provider agency overseeing many area workshops. This connection as well as word of mouth through existing participants provided most of the referrals in Montgomery County. Unfortunately, the agency designated to assist in recruitment efforts did not prove to be as helpful.

Project staff reported many challenges. The age requirements made recruitment difficult, as there are many parents under the age of 60 caring for their adult children with disabilities who need support. Getting other agencies to collaborate was also very difficult. The county offices of mental health/mental retardation did not provide as much assistance as was anticipated. They should have been an excellent resource as they have knowledge of individuals in need of the services provided by this program. Staff reported that MR case managers had heavy caseloads and are very busy. They were always being told about new programs. They were overwhelmed and this program was put on the "back-burner" with referrals never being made. We would recommend that in the future, at the beginning of the project, better connections be made between the Area Agency on Aging and the County Office of Mental health/Mental Retardation.

There were other recruitment issues relating to the caregivers themselves. Many caregivers were afraid to share information related to finances. They did not want to share their income and were fearful that if they started this program they would lose services they received elsewhere. This made it difficult to get families involved with the program. It was also suggested that the amount of reimbursement a family could receive needed to be increased. Many families did not see the two hundred dollar a month maximum as being worth the effort.

Some suggestions were made regarding how recruitment could have been done differently. More time was needed to get the program up and running. There should have been more efforts placed on advertising. Better education and more concrete information regarding the mission of the program, who can participate in the program, and what was involved with the program was needed. There could have been more emphasis placed on agencies to recruit individuals. There was little communication between the disability agencies and the aging agencies. The area agencies on aging should have shared the fact that they were not getting the number of the referrals they were anticipating. If this information was communicated more referrals may have been made.

It was suggested that the project would have been more successful if it were run through a disability organization or private contractor with more disability-related contacts. These groups have a better understanding of the disability community and the related service system. They also have experience with outreach and providing services to this population. It was also suggested that prior to the information sessions, supports coordinators should have been told to have consumers in mind that they may want to refer to the program. Doing this could have led to a more active effort on the part of the supports coordinators, as they would have already done the work involved in finding potential referrals.

The retention rate for the program once caregivers were enrolled was excellent. Staff attributes this to frequent check-ins with the caregivers either by home visits or phone calls, the ease of the program in terms of paperwork and the reimbursement itself. Frequent check-ins provided the caregivers with a peace of mind that someone is looking out for them and they were happy to have whatever extra money they could especially since most were on a fixed income.

Meeting the Caregivers Needs

A variety of different supports and services were reimbursed through the Elderly Caregiver Project. Reimbursements for over-the-counter medication, vitamins, respite, and homemaker services (house cleaning, lawn care, snow removal) were commonly provided. There were some challenges however, to providing reimbursement. The kind of services and supports that could be reimbursed weren't always clear to the caregivers or even to the care managers. There was no list of possible services or a description of what could be reimbursed. The guidelines followed Chapter 20 Caregiver Support Program guidelines, which focused on family members caring for older adults. Program coordinators reported that these guidelines didn't allow for many of the services that were requested by these caregivers. These services, such as lawn care, ended up being reimbursed in many cases as they were seen as necessary services. Care managers stated that they often advocated for their families to get the reimbursement they requested. Eventually there were few requests denied. Again, we assume that preparing a list of services, although helpful on the one hand, may constrain people's choices and creativity on the other hand. With regard to the care managers, more direction and training is needed so that they consistently know what is reimbursable.

It was reported that the caregivers needed a lot of coaching in order for them to save receipts and log services for reimbursement. Care managers stated that it was often difficult for them to find things for which the caregivers should be reimbursed. Many of the families have been on their own for so long they couldn't see how the little bit of reimbursement they would receive would really help them. Others were afraid to "use too much."

One of the supports needed by all the caregivers was a difficult one to address by this program. A major concern of the caregivers is that of the future and what will happen to their child after they die. Care managers stated that they tried to support the caregivers by providing referrals to lawyers to develop wills. They stated that they also attempted to help the caregivers start to look for group homes and other placements, but frequently the placement agencies weren't cooperative seemingly because care managers represented the aging population and not the mental retardation system. Again, a connection to the MH/MR system would have been helpful, in that caregivers should have been apprised to complete a Prioritization of Urgency of Need for Supports (PUNS) form, which is how individuals gain access to the supports provided through the MR system.

General Observations

Through interaction with caregivers in the interviews, it was recognized that elderly caregivers of adults with disabilities are frequently underserved, making programs such as this necessary. Many of these individuals receive little outside services and have few people they can rely on for support. These caregivers typically do not have the resources necessary to find services, and their values and past experience contribute to a refusal to ask for assistance.

Although all of the caregivers were grateful for the support they were receiving and many stated that more funding was necessary to assist this population, they commented on the reasons that they did not use all that was available. The most common rationale was that they didn't want to use too much now because they were getting by, and recognized they may need support in the future. Other individuals stated that they did not want to use funding that could be used to help someone that needed it more than them. Some mentioned that they needed more support but didn't fully understand what could be reimbursed so they didn't ask.

It was difficult for the caregivers to distinguish where certain supports came from and were often unable to distinguish between a support they received from this program and one received through MH/MR or a local disability agency. Better caregiver education was needed to promote active involvement and promote awareness regarding the programs they receive services from. The caregivers needed to be provided with training describing how this and other programs can help them to care for themselves and their family members with disabilities. They also needed to be provided with a detailed description of the supports and services that could be reimbursed by the program.

Greater collaboration between the county offices of mental retardation and the area agencies on aging is necessary to support caregivers of adults with disabilities. It is recommended that all caregivers be referred to Mental Health/Mental Retardation. Both groups have expertise in providing supports to the individuals they serve and are aware of the resources that are available to consumers. In cases such as this, both populations are being served together. Partnership between the organizations would lead to greater realization that services needed by caregivers and care recipients benefit both parties in some way, emotionally, physically, and/or financially. The groups should coordinate their efforts in order to provide supports for the entire family. In turn, greater family involvement would occur and programs such as this would see a better rate of success.