

# Consumer Direction Report



Consumer Perspective

Pre-Consumer Perspective

Human Service  
Professional Perspective

February 2005

*A report on the findings of consumer direction surveys disseminated throughout the Commonwealth under a project funded by the Robert Wood Johnson Foundation in collaboration with the National Association of the State Units on Aging and the National Council on Aging.*

PENNSYLVANIA  
DEPARTMENT OF  
**AGING**



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Executive Summary

**Introduction**

The National Association of State Units on Aging (NASUA) awarded a “Promoting Consumer Direction in Aging Services” project grant to the Pennsylvania Department of Aging (PDA). The grant provided an opportunity to assess Pennsylvania’s Home and Community-Based Service system approach to consumer choice and control and to identify opportunities for improvement.

Consistent with grant requirements PDA formed a partnership of stakeholders and utilized the *Consumer Direction Tool Kit* to help gather information regarding consumer direction in PDA’s home and community based service programs. Using the Kit, the Department and its stakeholder partnership developed three surveys to facilitate feedback from three groups: currently participating consumers (presently enrolled in services), stakeholders (age-appropriate but non-participating individuals), and provider/agency administrator/human service professionals.

**Methodology**

Survey focused on four key concepts: *Opportunity, Meaningful Participation, Independence, and Financial Security and Other Safeguards*. Surveys were distributed by the stakeholder partnership at various public events and/or meetings deemed appropriate for the project. Venues included participating consumers in active caseloads, Aging Expos, county specific meetings with diverse populations, senior centers, and training sessions of professionals in the human service field ranging from administrator to caseworker. Short project timeframes limited the time needed for substantial study. Accordingly, the primary goal was to obtain representative feedback from each of the targeted groups. Completed surveys were returned to PDA for analysis and are attached to this report. Sections are readily identified using the key concepts of *Opportunity, Meaningful Participation, Independence, or Financial Security and Other Safeguards*.

**Purpose**

The purpose of this report is to relay the results of the analysis conducted by PDA personnel and the recommendations for action from the stakeholder partnership to be addressed as items for reform within the system. The Reporting format focuses the reader on the results of each correlating survey section/key con-

cept, allowing a much clearer comparison between the survey groups and their thoughts per key concept.

**Principal Findings**

Each of the three surveys achieved a broad level of feedback. Surveys were received from across the state and included multiple types of potential consumers, current consumers and levels of providers of care. This broad response was accomplished through the dedication of the stakeholder partnership guiding PDA with this project. Their assistance assured diversity among the respondents within Pennsylvania’s home and community-based system. The majority of survey respondents provided positive feedback regarding consumer direction in long-term living services. Negative comments were limited to a few.

**Opportunity**

While the majority of consumer respondents reported that they were aware of programs available to assist them, fewer reported being certain about the first step they would have to take to obtain these services and assistance.

The Provider survey was designed to determine whether providers support consumer direction under Pennsylvania’s OPTIONS and PDA Waiver programs. Finding revealed that while providers are actively discussing consumer direction, few believe that adequate consumer-oriented information is available.

**Meaningful Participation**

Questions in this section were designed to discover whether or not current, as well as potential, consumers want to participate in service decisions and if they want to be involved in the development of a service plan. Participating consumers were asked if they had been given the choice prior to beginning services. Responses from both groups demonstrated an overwhelming yes to both.

Providers were presented with similar questions to determine whether the concept of consumer direction is being actively practiced and/or if it is agreeable with the provider. The majority (94 percent) of providers responded in a positive manner. The remaining 6 percent admitted they have encountered challenges when implementing consumer direction, but that they had no reservations about the intention of consumer direction.

*Executive Summary*

*Independence*

With regard to Independence, the consumer-oriented survey questions were designed to focus on the level of decision-making afforded to individuals managing their home and community living services. Questions focused on the ability to hire, manage and fire workers. In each of the three questions, over 50 percent of potential consumers responded in favor of having this authority. Similarly, over 50 percent of the currently participating consumer-respondents reported that the three options had been presented to them.

Provider survey questions were designed to ascertain the overall support consumers could expect to receive from providers across the Commonwealth. Not less than 72 percent of provider-respondents reported that consumers “are” participating or “should.”

*Financial Security and Other Safeguards*

This section afforded consumers an opportunity to provide issues and/or circumstance that would make the idea of receiving home and community based services and supports more appealing and secure. The majority of potential consumers (88 percent) reported that they would like more information/education regarding consumer direction while 68 percent of current consumers stated that adequate information was available. Twenty-two percent (22%) of respondents indicated that they would accept services through the state because of their expectation of higher quality services. This was also the most frequent answer given. Potential consumers replied at a rate of 81 percent that they would like to take part in the monitoring of their services.

Providers were afforded an opportunity to comment on local, state, and federal guidelines. Overall providers reported guidelines were adequate in meeting the needs of consumers. Suggestions for change were limited and included:

- The need for more funding;
- The need for an aggregate cap in the Waiver (implemented in SFY 04-05);
- The need to do away with estate recovery in the Waiver;
- The need to allow a spouse to be a paid employee;
- The need to exempt adult daily living services from cost sharing requirements.

*Conclusions and Recommendations*

Responses seemed to evidence that Pennsylvania is actively practicing and encouraging consumer direction. However, issues raised under each section of the survey demonstrated a common factor: a widespread need for training and education on Consumer Direction. There seems to be a lack of consistent information across the state among providers and consumers of home and community-living services and supports.

In this context, it is recommended that the PDA and the Area Agencies on Aging continue to emphasize the importance of consumer-directed services and find ways to more effectively institutionalize this approach in their ongoing efforts to implement and enhance long-term living services and supports.

It is also recommended that a training module focused on consumer direction be developed that contains sections addressing consumers, potential consumers and providers. The module should be designed with input from the three populations so that it addresses the concerns of all those who are involved while maintaining a strong consumer focus.

The training should be designed to permit replication to Pennsylvania’s counties. This approach will promote consistent training and understanding of consumer direction across the system. Training modules should be reviewed every six months until finalized.

## Introduction

The Pennsylvania Department of Aging (PDA) applied to the National Association of State Units on Aging (NASUA) and was awarded a grant to participate in the “Promoting Consumer Direction in Aging Services” project. The grant is an opportunity to assess PDA’s Home and Community-Based Service system and identify opportunities for increasing consumer choice and control.

## Purpose

The purpose of the following report is to relay the results of the analysis conducted by PDA personnel and the recommendations for action from the stakeholder partnership to be addressed as items for reform within the system. Each survey was divided into the concepts found within the Consumer Direction Tool Kit. Likewise, this report is divided into the same sections and contains the results of each correlating survey section. This method allowed a much clearer comparison between the survey groups for items specific to each concept.

## Methodology

The Pennsylvania Department of Aging (PDA) in collaboration with the Stakeholder Partnership developed specifically for the “Promoting Consumer Direction in Aging Services” project, utilized the *Consumer Direction Tool Kit*, provided through the grantor, to develop three surveys to facilitate feedback from Currently Participating Consumers (presently enrolled in services), Stakeholders (age-appropriate but non-participating individuals) and Provider/Agency Administrator/ Human Service Professionals.

Each survey was built around the concepts found within the Consumer Direction Tool Kit; *Opportunity, Meaningful Participation, Independence and Financial Security and Other Safeguards*. After designing each survey, they were distributed by the stakeholder partnership at various public events and/or meetings deemed appropriate for the project. The venues included participating consumers in active caseloads, Aging Expos, a variety of county specific meetings that would include diverse populations from the county, senior centers and train-

ing sessions of professionals in the human service field ranging from administrator to caseworker. Though the project did not permit the time needed for substantial study, feedback consistent with the type derived from a public forum was the primary goal. After the surveys were completed, the members of the partnership returned them to PDA to be entered into a database for analysis. The surveys are included in this report. For the purpose of this report and the audience viewing it, each section is labeled to readily identify it as *Opportunity, Meaningful Participation, Independence or Financial Security and Other Safeguards*.

It is important to note that percentages shown are per the amount of responses received for each individual question, not the total amount of surveys received for each category.

## Description and Demographics Captured by Each Survey

*The CD Stakeholders—Potential Consumers Survey* consists of 12 questions and a final section for comments. To ascertain the configuration of the population captured by the survey, participants were asked their county of residence, age and gender. A total of 642 surveys were returned to PDA. The surveys were received from 20 counties, or 38 percent of Pennsylvania counties. The age of the respondents ranged from 33 to 96 with the majority of respondents, 69 percent, being between the ages of 66 and 81. Though seven percent of respondents left this question blank, the most commonly reported age was 78. Out of the 642 surveys, 559, 13 percent of respondents, completed the question regarding gender with 28 percent reporting to be male and 72 percent reporting to be female.

*The Currently Participating Consumer Survey* consists of 13 questions and a final section for comments. Again, to gain perspective on the population captured by the survey, participants were asked their county of residence, age, gender and the name of the program he/she is currently enrolled. A total of 261 surveys were returned to

PDA. The surveys represented nine counties across the state. The ages of consumers responding ranged from 60 to 111 with the most commonly reported ages falling between ages 76 and 86. The reported gender of responding consumers is consistent with the previously

*It is important to note that percentages show are per the amount of responses received for each individual question, not the total amount of surveys received for each category.*

discussed survey with 24 percent of consumers reporting to be male and 76 percent reporting to be female. When asked what program the consumer was currently enrolled in, 87 percent of those who completed the question responded they are currently enrolled in either the PDA 60+ Medicaid Waiver program (64 percent) or the PDA OPTIONS (23 percent) program. Though the Domiciliary Care Program and the PA Family Caregiver Program were each mentioned totaling an additional 1 percent of respondents, the majority of remaining responses cited specific services including, home health, housekeeping, personal care, respite, senior centers and a respondent who was unsure.

The *Provider/Agency Administrator/Human Service Professional Perspective*, hereafter referred to as the *Provider Perspective Survey*, consisted of 10 questions and a section for comments. The first three questions were designed to gauge what type of providers the survey was able to reach at the various levels of organizations across the Commonwealth. A total of 214 surveys were returned to PDA. The diversity of level and type of provider was more than would have been accomplished in a closed forum. Individuals described themselves as intake workers, assessors, aides, case managers, care managers, supervisors, directors, deputies, vice presidents, CEOs and owners. Respondents also took the time to identify themselves further as being social workers, nurses, budget staff, ombudsman, etc.

**Opportunity**

With regard to Opportunity, the *CD Stakeholder–Potential Consumer* survey addressed if the individual was aware of programs available to assist them in the event a need arose and what their first step would be to obtain assistance. As illustrated in the following table, the survey revealed that 327 (54 percent) of respondents felt they knew where to call, while 149 stated they did not know where to call and 130 being “unsure.” When asked where the respondent would call, 242 (49 percent) reported their first step would be to call the local Area Agency on Aging (AAA). An additional 16 percent responded with calling various parts of the system that, though not a direct link, would connect with the system. Additional answers reflecting a lack of knowledge of available programs comprised 21 percent of responses while another 14 percent simply responded with “don’t know.”

<b>CD Stakeholder–Potential Consumer Survey</b>	
<b>I am aware of where to call for service.</b>	
Yes . . . . .	327
No . . . . .	149
Unsure . . . . .	130
<b>TOTAL # RESPONSES . . . . .</b>	<b>606</b>
<b>I would call ...</b>	
AAA . . . . .	242
Miscellaneous system links . . . . .	79
Answers reflective of lack of knowledge regarding system . . . . .	104
“Don’t know” . . . . .	71
<b>TOTAL # RESPONSES . . . . .</b>	<b>496</b>

In the *Participating Consumers* survey, with a total of 260 respondents, there were three separate questions as follows, “Are you aware of programs available to assist in maintaining community activities,” “My care manager explained consumer direction to me” and “I understand the consumer direction model of receiving in-home services.” As illustrated below, in the first question, consumers responded at a total of 223 (86 percent), claiming awareness of available programs. For the second question, 227 (88 percent) stated that the care manager explained consumer direction and in the final question, 204 (80 percent) understood the consumer direction model.

<b>Participating Consumers Survey</b>	
<b>Question</b>	<b>Yes response/ # of responses</b>
I am aware of the programs available to assist me . . . . .	223/260
My care manager explained consumer direction to me . . . . .	227/258
I understand the Consumer Direction Model of receiving in-home services . . . . .	204/256

In the *Provider Perspective* survey, the questions were designed to assist in determining if the providers supported consumer direction by assuring that consumers were explained all options of receiving service under

the OPTIONS and PDA Waiver program. As the chart below illustrates, a total of 127 (63 percent) of the providers reported “yes,” available options are discussed while 24 (12 percent) reported “no,” options are not discussed. Those that do not discuss options are all found within 11, or one-third, of the counties participating in this survey. A further 47 (23 percent) reported “unsure” while five (2 percent) felt this question was “not applicable.” From these numbers it may be assumed providers are actively discussing consumer direction options but there is reason to target counties that reported to the contrary and inquire further at a later date. When asked about the availability of comprehensive information for consumers, 99 (48 percent) responded that the “information is available,” 47 (23 percent) replied “no,” and 56 (27 percent) were “unsure.” Also, four (2 percent) did not feel this question was applicable to them. Many providers supplied comments, however, explaining that they do not feel there is adequate information geared toward consumers.

<b>Provider Perspective Survey</b>	
<b>Agency-directed and consumer-directed service options are discussed.</b>	
Yes . . . . .	127
No . . . . .	24
Unsure . . . . .	47
N/A . . . . .	5
<b>TOTAL # RESPONSES . . . . .</b>	<b>203</b>
<b>Consumer direction information is available to consumers in various formats.</b>	
Yes . . . . .	99
No . . . . .	47
Unsure . . . . .	56
N/A . . . . .	4
<b>TOTAL # RESPONSES . . . . .</b>	<b>206</b>

**Meaningful Participation**

Questions in the Meaningful Participation section, illustrated in the following table, were designed to discover whether or not current, as well as potential, consumers want to participate in service decisions and if they want to be involved in the development of a serv-

ice plan. In the *CD Stakeholder–Potential Consumer* survey, a resounding 372 (63 percent) respondents stated they “always” want the opportunity to participate in service decisions with another 125 (21 percent) stating they wanted to participate in service decisions but “through a family member.” A few individuals, 49 (8 percent), want to “sometimes” participate in these decisions while seven (1 percent) “never” want to participate and 36 (6 percent) were “unsure.”

These answers directly relate to the 335 (58 percent) of responses indicating a desire to “always want to be involved in the development of a care plan” with 116 (20 percent) who want their “family to be the primary” participants, nine (2 percent) replied “never” and 47 (8 percent) were “unsure.”

<b>CD Stakeholder–Potential Consumer Survey</b>	
<b>Prefer to participate</b>	
Always . . . . .	372
Sometimes . . . . .	49
Through family member . . . . .	125
Never . . . . .	7
Unsure . . . . .	36
<b>TOTAL # RESPONSES . . . . .</b>	<b>589</b>
<b>Want AAA to involve me</b>	
Always . . . . .	335
Sometimes . . . . .	74
Through family member . . . . .	116
Never . . . . .	9
Unsure . . . . .	47
<b>TOTAL # RESPONSES . . . . .</b>	<b>581</b>

In the *Participating Consumers* survey respondents were asked if “the choice to use a consumer-directed option was given,” how he/she would “prefer to participate in decisions regarding needs,” and the degree to which the consumer wants the “AAA to involve them in decisions about developing their plan of service.” When asked if a choice was given to use the consumer-directed option, 211 (83 percent) respondents indicated “yes,” 16 (6 percent) replied “no,” 21 (8 percent) were “unsure” and six (2 percent) of respondents “did not feel this way applicable to them.”

<b>Participating Consumers Survey</b>	
<b>I was given a choice to use a consumer-directed option by my care manager.</b>	
Yes . . . . .	211
No . . . . .	16
Unsure . . . . .	21
N/A . . . . .	6
<b>TOTAL # RESPONSES . . . . .</b>	<b>254</b>

When asked to what degree consumers would like to participate, 182 (71 percent) replied “always,” 34 (13 percent) replied “sometimes,” 39 (15 percent) replied “through a family member” and three (1 percent) replied “unsure.” Though consumers were given the option to reply “never,” not one consumer did that. All but 1 percent of the consumers who replied to this question want active participation in decision-making regarding the care received in the home.

The majority of participating consumer-respondents, 189 (74 percent), when asked the degree to which the consumer would like the AAA to involve him/her in developing a plan of service, responded “always,” 30 consumers (12 percent) checked off “sometimes,” 31 (12 percent) indicated involvement through a family member while four (2 percent) were “unsure.” These numbers would indicate that, given the option, consumers want to participate in service decisions that affect their lives and in Pennsylvania, the majority of consumers currently participating in available programs have had the opportunity to discuss their options.

<b>CD Stakeholder–Potential Consumer Survey</b>	
<b>Would like to participate</b>	
Always . . . . .	182
Sometimes . . . . .	34
Through family member . . . . .	39
Never . . . . .	0
Unsure . . . . .	3
<b>TOTAL # RESPONSES . . . . .</b>	<b>258</b>

<b>Would like AAA to involve me</b>	
Always . . . . .	189
Sometimes . . . . .	30
Through family member . . . . .	31
Never . . . . .	0
Unsure . . . . .	4
<b>TOTAL # RESPONSES . . . . .</b>	<b>254</b>

In the *Provider Perspective* survey, providers were presented with the same questions turned around to extract whether providers are supporting consumers who want to participate in service decisions including the decision regarding which services are best for the consumer. The survey asked whether the “AAA involves the consumers in decisions about coordinating their service,” if “consumers should be able to choose the amount and type of service to meet their needs,” and if “assistance is provided to consumers to help in selecting services that meet their needs.” The response to the first question, as shown in the table below revealed that 86 percent (181) of respondents have had experience with the AAA involving consumers in decisions regarding the coordination of their care with 85 of those responses coming from the AAAs themselves. Only 3 percent (7) replied “no” and 10 percent (22) were “unsure.”

<b>Provider Perspective Survey</b>	
<b>The AAA involves consumers in decisions about coordinating care.</b>	
Yes . . . . .	181
No . . . . .	7
Unsure . . . . .	22
N/A . . . . .	1
<b>TOTAL # RESPONSES . . . . .</b>	<b>214</b>

As shown in the following table, a total of 195 (93 percent) providers demonstrated their support of consumer choice by selecting consumers “may” or “should” “choose the amount of service to meet their need.” The remaining 13 (6 percent) of providers replied that consumers “should not be able to choose the amount and type of service to meet their need.”

The respondents to this question self-reported as care managers, RNs, and directors from varied organizations. The reasons cited include lack of funding and fear of consumers taking advantage of the system. One suggestion, “to form a team with the consumer,” was offered.

The final question in the *Provider Perspective* survey for this section, also illustrated in the table below, asks providers if “assistance is provided to consumers to help them select services that meet their needs.” Providers could answer “yes, no, unsure or not applicable.” One hundred eighty-three (88 percent) reported “yes”, they provide assistance while six (3 percent) replied “no” and 19 (9 percent) were unsure if assistance is provided. Of the 183 reporting to know of assistance provided to consumers in selecting their services, 81, less than half, were AAAs. From this information it is possible to assume an overall support from providers in providing assistance to consumers while involving them in developing a service plan to fit their unique needs.

*holder–Potential Consumer* survey, consumers were asked for their preference regarding acting independently in the “hiring, firing and management of workers, should they ever require services.” The majority of respondents expressed a desire to do so as shown below.

<b>CD Stakeholder–Potential Consumer Survey</b>			
	Hire	Manage	Fire
Yes	269	274	230
No	75	56	62
Unsure	159	129	116
N/A	27	19	23
Blank	112	164	211

Interesting to note is that in the last question under this section asking if an individual would like to “hire a family member in the event he/she required services,” again, the majority of respondents, 319, replied “yes.” The remaining responses were equally split between “no” (144) and “unsure” (143).

In the *Participating Consumers* survey respondents were asked not about preference, but instead, whether the option to “hire, fire and manage their worker was offered” by their provider. The majority of respondents expressed that they had been offered to participate in these functions.

<b>Participating Consumers Survey</b>			
	Hire	Manage	Fire
Yes	132	143	129
No	35	24	33
Unsure	31	28	28
N/A	45	41	41
Blank	17	24	29
<b>TOTAL</b>	<b>260</b>	<b>260</b>	<b>260</b>

Though the majority of consumers have been offered these options, further study would be needed to understand why some either were not given the option or are unsure if they have been offered to participate in that way.

Consumers were then asked if “they felt family

<b>Provider Perspective Survey</b>	
<b>Consumers ... choose amount and type of services to meet needs.</b>	
Can .....	84
Should .....	111
Should not be able to .....	13
N/A .....	5
<b>TOTAL # RESPONSES .....</b>	<b>208</b>
<b>Assistance is provided to consumers in selecting services to meet needs.</b>	
Yes .....	183
No .....	6
Unsure .....	19
N/A .....	1
<b>TOTAL # RESPONSES .....</b>	<b>209</b>

**Independence**

With regard to Independence, the survey questions were designed to intentionally focus on the level of decision-making being given to individuals affecting their care and life in the community. In the *CD Stake-*

members should be able to provide services” and “if the family member should be paid.” Of the consumers who replied to this question, 144 or 57 percent “felt that family members should be able to provide services,” with the remaining responses divided equally at 21 percent each, between those who “felt that family should not provide service” (55) and those who were “unsure” (54). Concerning family being paid to provide service, 120 respondents (47 percent) felt “family should be paid” while 86 (34 percent) “didn’t feel family should be paid” and 47 (19 percent) were “unsure.” These numbers are very close. Some comments included “I do not want to be a burden on my family.” Other comments indicated a lack of trust for family dealing in their affairs. Also, there were those consumers who revealed they do not have any family left to ask for assistance. On the other hand, there were also strong statements in favor of hiring family members and paying them. Comments such as “I wouldn’t feel so bad about asking for help” seem to support the argument that a consumer would not wait until a crisis if they could pay the family member who cares for them.

In the *Provider Perspective* survey, the questions were designed to ascertain the overall support consumers may expect to receive across the Commonwealth from the various types of providers. It is important to understand how much the provider visualizes the consumer participating in their care as it relates to the community.

Providers were asked if consumers “are, should, or should not be able to select, manage, and dismiss their worker.” The responses are illustrated below.

<i>Provider Perspective Survey</i>			
	Select	Manage	Dismiss
Are	56	46	62
Should be able to	118	96	103
Should not be able to	28	57	31
Blank	12	15	18
<b>TOTAL</b>	<b>214</b>	<b>214</b>	<b>214</b>

From the responses received it appears that providers are largely supportive of consumers having the option

to select, manage and dismiss their worker. Some are currently providing these options. The providers who noted that consumers should not be given this authority commented mostly that the consumer would not have the expertise to choose the appropriate worker or stay within funding limits. There was also concern raised over the work force shortage. Comments ranged from the possibility of a consumer becoming too difficult or demanding due to inexperience and exhausting local supply of available workers, to a consumer not having the resources to structure an appropriate backup system. All of the concerns are considered valid; however, they could be construed as further evidence of a lack of information regarding consumer direction and further need for training.

### *Financial Security and Other Safeguards*

Within the Financial Security and Other Safeguards section the intention was to highlight traditional responses from potential consumers regarding issues and/or circumstance that would make the idea of receiving home and community-based care more appealing and secure. The questions consisted of two close-ended questions asking the respondents if “information and/or education regarding available programs was wanted,” and if they wanted to “provide input to monitoring methods,” and two open-ended questions which asked the respondent to state a reason why they would be either comfortable or uncomfortable receiving services from the state.

In the *CD Stakeholder–Potential Consumer* survey, respondents demonstrated a preference for education and training with 531 (88 percent) checking off “yes” and 23 (4 percent) of respondents replying “no.” The remaining 8 percent were “unsure.” The response was similar in giving input to monitoring. A total of 479 (81 percent) of respondents “would like to give input to monitoring” while 33 (6 percent) replied “no” and 80 (14 percent) remain unsure. When asked to fill in the blank regarding a reason to accept or not accept services from the state, 429 respondents gave reasons to accept service and 119 gave reasons not to accept services. Various answers were given which were then broken down into topics demonstrated by the following table:

Alone	7	2%
<b>Anticipates quality</b>	<b>96</b>	<b>22%</b>
Don't know	25	6%
Entitled as senior citizen	15	3%
Family works	2	0.4%
Feel comfortable	9	2%
Grouped w/seniors	1	0.2%
I can sue	1	0.2%
If family provides care	3	1%
Insurance	1	0.2%
Last resort	15	3%
<b>Limited income</b>	<b>56</b>	<b>13%</b>
Local	1	0.2%
Maintain independence	4	1%
<b>Need more help</b>	<b>84</b>	<b>20%</b>
<b>Paid taxes</b>	<b>61</b>	<b>14%</b>
Yes	48	11%
Total responses	429	67%
<b>Blank</b>	<b>213</b>	<b>31%</b>
<b>TOTAL SURVEYS</b>	<b>642</b>	

Though the answers could possibly be broken down further, some respondents stated their answer in such a specific manner that if stated otherwise would not be sufficient. As demonstrated in the above table, the most popular answer was that the respondents “expected quality from the state” in the form of training of staff, regulations or knowledge of the system as well as being more prepared to serve their needs. The second highest response indicates that individuals would call on the state “if they needed more help than they were able to get themselves.” The third largest response comprises those who feel they “are entitled to services due to having paid taxes all their lives.” This group includes those who responded that paying state and or local taxes entitled them to services. Of most concern, though only 3 percent of respondents, it is unfortunate that individuals will not accept services from the state unless it is the “last resort.” These individuals are typically those who will wait until there is a crisis before seeking services and more often than not, be steered toward a nursing facility. The stakeholder partnership recognizes this group as a priority in the system.

Among reasons to not accept services, the highest response rate was 28 (24 percent), indicating “don’t know,” and the next highest response of 15 (13 percent) being “no.” Among the top three responses that are descriptive enough to attempt to address are “my care is my personal responsibility” and “state overly directive.” The first is self-explanatory; however, with the second, 11 respondents made comments including “the state programs tell you where, when and who,” and “they’re too pushy.”

To further analyze this answer it was examined against the previous question regarding reasons to accept services. Of the 11 respondents, one commented on the previous questions that “services would only be accepted from the state as a last resort,” five responded in agreement to accept services because “they have paid taxes and are entitled,” two would accept services because “greater quality from the state is anticipated,” one would accept services to “maintain independence,” one would accept services due to “limited income,” and one left this blank. However, six out of the 11 knew where to call for assistance when asked earlier in the survey, stating they would call the AAA. The combination of these answers suggests that though there may be negative feelings regarding state involvement in care, they are minimal. The stakeholder partnership recognizes the need to address this concern.

In the *Participating Consumers* survey it was decided to focus on the availability of training and educational material to understand how these items may affect the consumer’s ability to feel more secure in their home and community while receiving services. Consumers responded with 172 (68 percent) of respondents stating there was “clear educational information regarding consumer-directed service made available,” 30 (12 percent) stated “no,” information was not available, 46 (18 percent) were “unsure” and six (2 percent) felt this was not applicable to their situation. The next question, if education or training information was provided regarding programs for which he/she may be eligible, 195 (76 percent) consumers responded “yes.” This would mean more than half of the current consumers surveyed feel they have made a sound decision. A total of 28 (11 percent) replied “no,” and 33 (13 percent) replied “unsure.”

**Participating Consumers Survey**

**Clear consumer direction educational material was made available to me.**

Yes . . . . .	172
No . . . . .	30
Unsure . . . . .	46
N/A . . . . .	6
<b>TOTAL # RESPONSES . . . . .</b>	<b>254</b>

**Education or training information was provided to me regarding programs I may eligible for.**

Yes . . . . .	195
No . . . . .	28
Unsure . . . . .	33
<b>TOTAL # RESPONSES . . . . .</b>	<b>256</b>

The questions in the *Provider Perspective* survey for this section were designed to allow providers to state whether or not the state, federal and local guidelines enable consumers to receive services that meet their needs in order for consumers to remain in their home. Providers have the option to respond to the question then expand their thoughts in the “comments” section directly following the question. Note the results below.

**Provider Perspective Survey**

	State Guidelines	Federal Guidelines	Local Guidelines
Yes	144	129	140
No	38	38	31
Unsure	27	42	37
N/A	1	1	2

Overall, providers reported guidelines to be adequate in meeting the needs of consumers. The suggestions for change were limited. Most comments cited a lack of funding but there were also specific comments including the “need for an aggregate cap in the Waiver,” the “need to do away with estate recovery in the Waiver,” “allow a spouse to be a paid employee,” “make an exception for adult day care with cost sharing,” and another provider stated, “Public awareness should be heightened at all levels. Young people, mid-

dle aged, elderly. What’s out there? How can I get it? How can providers link together, fill in the gaps in care? How about marketing, like public service announcements?”

**Additional Information**

The final questions on the survey were extraneous information pieces designed to gather information commonly mentioned in conversations regarding implementation and success of consumer direction. The following questions were directed to potential consumers and current consumers. The first of these survey questions asked if it is felt “workers who provide services to consumers are not paid enough.” In the *CD Stakeholder–Potential Consumer* survey there were 503 responses to this question with 342 (68 percent) responding “true,” workers are not paid enough. The remaining responses were almost equally split between “false,” 83, and “don’t know,” 78. In the *Participating Consumers* survey 86 percent, 205 out of 238, of current consumers also replied “yes.” Whether or not the higher percentage is due to being more intimately involved with the system is unknown but clearly states consumer involvement and potential consumer desire to be involved.

The last question on both the *CD Stakeholder–Potential Consumer* survey and the *Participating Consumers* survey was multiple choice as follows:

- I understand the Consumer Direction Model of receiving in-home services is: (select all that apply):
  - a. The ability to direct my services and the workers who will provide them.
  - b. The ability to direct only the workers providing service to me.
  - c. The ability to direct only the services I receive.
  - d. Empowering consumers to interact with their community as they see fit.

Of the choices given, “a” and “d” were the desired choices. Though the responses to this question could be broken down in many ways, it was decided for the purpose of this survey to count how many times each was selected which will generate a greater number of responses than surveys, but also presents a better picture of how people generally feel.

<i>I understand the Consumer Direction Model of receiving in-home services is:</i>				
Survey Name	a	b	c	d
Potential Consumer	266	148	169	150
Participating Consumer	170	87	97	100

The survey responses would indicate that individuals have more than an idea of what consumer direction is in Pennsylvania.

### *Conclusions and Recommendations*

Responses seemed to evidence that Pennsylvania is actively practicing and encouraging consumer direction. However, issues raised under each section of the survey demonstrated a common factor: a widespread need for training and education on Consumer Direction. There seems to be a lack of consistent informa-

tion across the state among providers and consumers of home and community-living services and supports.

It is recommended that the PDA and the Area Agencies on Aging continue to emphasize the importance of consumer-directed services and find ways to more effectively institutionalize this approach in their ongoing efforts to implement and enhance long-term living services and supports.

It is also recommended that a training module focused on consumer direction be developed that contains sections addressing consumers, potential consumers and providers. The module should be designed with input from the three populations so that it addresses the concerns of all those who are involved while maintaining a strong consumer focus.

The training should be designed to permit replication to Pennsylvania’s counties. This approach will promote consistent training and understanding of consumer direction across the system. Training modules should be reviewed every six months until finalized.

*Consumer Direction Survey  
Currently Participating Consumers*

County of Residence: \_\_\_\_\_

Age: \_\_\_\_\_

Gender: \_\_\_\_\_

Current Program, if any, enrolled in: \_\_\_\_\_

PLEASE CIRCLE THE MOST ACCURATE ANSWER DESCRIBING YOUR SITUATION

1. I am aware of the programs available to assist me in maintaining my community activities.  
Yes/No/Unsure
2. My care manager explained consumer direction to me.  
Yes/No/Unsure/Not Applicable
3. I understand the Consumer Direction Model of receiving in-home services.  
Yes/No/Unsure/Not Applicable
4. I was given a choice to use a consumer directed option by my care manager.  
Yes/No/Unsure/Not Applicable
5. I prefer to participate in decisions regarding my needs.  
Always/Sometimes/Through a Family Member/Never/Unsure
6. I want the Area Agency on Aging to involve me in decisions about developing a plan of services for me.  
Always/Sometimes/Through a Family Member/Never/Unsure
7. I was given the option to:
  - a. Hire my own workers Yes/No/Unsure/Not Applicable
  - b. Manage my own workers Yes/No/Unsure/Not Applicable
  - c. Fire my own workers Yes/No/Unsure/Not Applicable
8. Family members should be able to provide services.  
Yes/No/Unsure
9. Family members should be paid to provide services.  
Yes/No/Unsure
10. Clear educational information regarding consumer directed service was made available to me.  
Yes/No/Unsure/Not Applicable
11. Education or training information was provided to me regarding the programs for which I may be eligible so that I can make good decisions regarding my services.  
Yes/No/Unsure



Consumer Direction Survey  
Potential Consumers

County of Residence: \_\_\_\_\_

Age: \_\_\_\_\_

Gender: \_\_\_\_\_

PLEASE ANSWER THE QUESTIONS BELOW AS IF YOU WERE IN NEED OF IN-HOME SERVICES TO CONTINUE LIVING AT HOME. CIRCLE THE ANSWER THAT MOST ACCURATELY DESCRIBES HOW YOU FEEL.

1. Should I need services in my home, I am aware of the programs available to assist me in maintaining my community activities.  
Yes/No/Unsure
2. Should I need services in my home, I know how to apply for services in my community. As a first step I would \_\_\_\_\_.
3. I would prefer to participate in decisions regarding my needs.  
Always/Sometimes/Through a Family Member/Never/Unsure
4. I would want the Area Agency on Aging to involve me in decisions about developing a plan of services for me.  
Always/Sometimes/Through a Family Member/Never/Unsure
5. If I needed services, I would prefer to independently:
  - a. Hire my own workers Yes/No/Unsure/Not Applicable
  - b. Manage my own workers Yes/No/Unsure/Not Applicable
  - c. Fire my own workers Yes/No/Unsure/Not Applicable
6. Should I need services I would like to be able to hire family members to provide services.  
Yes/No/Unsure
7. Should I need services I would want education or training information regarding the programs for which I may be eligible so that I can make good decisions regarding my services.  
Yes/No/Unsure
8. I would like to give input into the ways home service programs can be monitored.  
Yes/No/Unsure
9. I would feel comfortable accepting services from the state because (please provide a short answer)

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_



*Consumer Direction Survey  
Human Service Professional Perspective*

Title/Position: \_\_\_\_\_

Type of Organization: \_\_\_\_\_

County: \_\_\_\_\_

PLEASE CIRCLE THE MOST ACCURATE ANSWER

1. The two options of service—agency-directed and consumer-directed—are explained to consumers desiring Personal Assistance Services under OPTIONS and the PDA Waiver.  
Yes/No/Unsure/Not Applicable
2. Comprehensive information regarding consumer-directed service is readily available to consumers in various formats.  
Yes/No/Unsure/Not Applicable
3. The Area Agency on Aging involves consumers in decisions about coordinating its service.  
Yes/No/Unsure/Not Applicable
4. Consumers can/should/should not be able to choose the amount and type of service to meet their needs.
5. Assistance is provided to consumers in selecting services to meet their needs.  
Yes/No/Unsure/Not Applicable
6. Consumers:  
are/should be/should not be given the option to select workers.  
are/should be/should not be given the option to manage workers.  
are/should be/should not be given the option to dismiss workers.
7. Consumers are given information about local programs available to meet their needs.  
Yes/No/Unsure/Not Applicable
8. Current state guidelines allow consumers to receive the services that meet their needs in order to remain in their own homes. Yes/No/Unsure/Not Applicable
9. Federal guidelines allow consumers to receive the services that meet their needs in order to remain in their own homes. Yes/No/Unsure/Not Applicable
10. Local guidelines allow consumers to receive the services that meet their needs in order to remain in their own homes. Yes/No/Unsure/Not Applicable

11. Additional Comments:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

*Stakeholder Partnership*

***CONSUMERS***

**John L. Tunney, Jr.**

**Peggy O’Neill**  
Aging Connection

**Joan Dougherty**

***CONSUMER ADVOCACY AGENCIES***

**Diane Menio**  
CARIE—Center for Rights and Interests of the Elderly

**Barbara Dickman**  
AARP—American Association of Retired Persons

**Sandra L. Weber**  
PA SILC—Pennsylvania State Independent Living Council

**Bob Rosenberger**  
Alzheimer’s Association Greater Pennsylvania Chapter

**Susan Tomasic**  
PA State Independent Living Council

**Mary Anne Kelly**  
SW PA Partnership for Aging

**Pedro Rodriguez**  
Alliance for Retired Americans

**Tina Trainer**  
Abilities In Motion

***HOME CARE AGENCIES***

**Vicki Hoak**  
PA Homecare Association

***PENNSYLVANIA DEPARTMENT OF PUBLIC WELFARE***

**Paul Culbertson**  
Supervisor, Pre-Admission Assessment, Long-Term Care Client Services

**Carole Rebert**  
Chief Operating Officer, Office of Medical Assistance Programs

**Ed Spreha**  
Special Assistant to Deputy Secretary OSP

***AREA AGENCIES ON AGING***

**Barbara Coffin**  
Co-chair, Berks County Area Agency on Aging

**Steve Touzell**  
Philadelphia Corp. for Aging

**Darlene Burlazzi**  
Allegheny County Area Agency on Aging

**Holly Kyle**  
Union/Snyder County Area Agency on Aging

**John Kordish**  
Executive Director, Clearfield County Area Agency on Aging

**Jody Yarger**  
Clearfield County Area Agency on Aging

**Tim Landrin**  
Southwestern PA Area Agency on Aging, Inc. (covering Fayette/Greene/Washington counties)

***PA DEPARTMENT OF AGING***

**Ivonne Bucher**  
Co-chair, Director, Office of Community Services and Advocacy

**Rebecca Snyder**  
Management Consultant

**Kathy Skrinak**  
Clinical Consultant

**Dan McGuire**  
Director, Bureau of Home and Community-Based Services

**Dale Laninga**  
Executive Director, Inter-governmental Council on Long-Term Care

**Bob Hussar**  
Chief, Consumer Protection Division

**John Detman**  
Chief, Consumer Community Support Services Division

**Kelly Allen**  
Long-Term Care Systems Planner

Events Held to Distribute Surveys

**AUGUST**

**AAA Training**

DESCRIPTION PDA PAS  
DATE August 27, 2003  
TIME 10 a.m. to noon  
PLACE Montgomery AAA  
CONTACT/  
STAKEHOLDER Tina Trainer • 610-376-0010  
CONTACT

**SEPTEMBER**

**Consumer Direction in HCBS for Older Adults  
Special Educational Forum**

DESCRIPTION Older adults, family members and providers from entire range of service system interested in finding out more about consumer choice and consumer direction.  
DATE September 8, 2003  
PLACE Warrendale, Pa.  
CONTACT/  
STAKEHOLDER Mary Anne Kelly • 724-779-3201  
CONTACT

**Fiscal Training**

DESCRIPTION Training Western Fiscal Agents and Butler AAA  
DATE September 9, 2003  
TIME 9 a.m. to 3 p.m.  
PLACE Three Rivers CIL  
CONTACT/  
STAKEHOLDER Tina Trainer • 610-376-0010  
CONTACT

**Washington County Senior Expo**

DESCRIPTION Sponsored by Rep. Timothy Solobay  
DATE September 18, 2003  
TIME 10 a.m. to 3 p.m.  
PLACE Washington Crown Center  
Washington, Pa.  
CONTACT/  
STAKEHOLDER Tim Landrin  
CONTACT SW PA AAA  
Eastgate 8  
Monessen, PA 15062  
724-684-9000 x4477  
e-mail: landrin@swpa-aaa.org

**SW PA AAA Advisory Council Retreat**

Meeting of older persons (consumers and non) who advise the AAA on various programmatic issues  
DATE September 23, 2003  
TIME 9 a.m. to 4 p.m.  
PLACE Mon Valley Community Health Center  
CONTACT/  
STAKEHOLDER Tim Landrin  
CONTACT SW PA AAA  
Eastgate 8  
Monessen, PA 15062  
724-684-9000 x4477  
e-mail: landrin@swpa-aaa.org

**OCTOBER**

**Second Annual Morris and Esther Glickstein  
Memorial Lecture—"Giving of Yourself Without  
Losing Yourself"**

DESCRIPTION Focus on direct care workers and family members  
DATE October 3, 2003  
PLACE Pittsburgh  
CONTACT/  
STAKEHOLDER Mary Anne Kelly • 724-779-3201  
CONTACT

**Senior Fitness Day**

DESCRIPTION Fitness event  
 DATE October 15, 2003  
 PLACE Phila. Zoo  
 34th & Girard Avenue  
 Philadelphia  
 CONTACT/  
 STAKEHOLDER Steve Touzell • 215-765-9000  
 CONTACT

**Latino Health and Information Fair for Seniors & their Caregivers**

DESCRIPTION Health fair for Latino older adults  
 DATE October 18, 2003  
 9 a.m. to 2 p.m.  
 PLACE Cardinal Dougherty High School  
 2nd & Godfrey Avenue  
 Philadelphia  
 CONTACT/  
 STAKEHOLDER Steve Touzell • 215-765-9000  
 CONTACT

**Distribution to AAAs for Senior Centers**

DESCRIPTION Senior Centers  
 DATE October 23, 2003  
 PLACE Ongoing participation (Counties include Blair, Huntingdon/Bedford/Fulton, Westmoreland, Lancaster, Franklin, Crawford, Lycoming/Clin-ton, Lehigh, Dauphin, Columbia/Montour  
 CONTACT Amy Schweitzer • 717-783-6207  
 STAKEHOLDER Kelly Allen  
 CONTACT

**NOVEMBER**

**Asian Health Fair**

DESCRIPTION Health fair for Asian older adults  
 DATE November 1, 2003  
 TIME 9 a.m. to 2 p.m.  
 PLACE Holy Redeemer Church  
 915 Vine Street  
 Philadelphia  
 CONTACT/  
 STAKEHOLDER Steve Touzell • 215-765-9000  
 CONTACT

**Senior Game Day**

DESCRIPTION Pool Tournament  
 DATE November 13, 2003  
 Dave & Busters  
 Delaware Avenue  
 Philadelphia  
 CONTACT/  
 STAKEHOLDER Steve Touzell • 215-765-9000  
 CONTACT

**Multi-County Consumer Gathering**

Lebanon, Schuylkill, Lancaster, and Berks counties  
 DATE November 21, 2003  
 TIME 1 p.m. to 5 p.m.  
 PLACE Mt. Aetna  
 CONTACT/  
 STAKEHOLDER Tina Trainer • 610-376-0010  
 CONTACT

**DECEMBER**

**Fourteenth SWPPA Annual Meeting**

DESCRIPTION SWPPA's annual membership meeting attended by older adults, numerous folks aged 50 to 65, family members and providers from the 10 counties of SW Pennsylvania  
 DATE December 5, 2003  
 PLACE Warrendale  
 CONTACT/  
 STAKEHOLDER Mary Anne Kelly • 724-779-3201  
 CONTACT



