



## Respite Care Association Study

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# Background and Methodology

## Background

Chamberlain Research Consultants Inc. was commissioned by the Respite Care Association of Wisconsin to conduct a research study to help inform future policy recommendations regarding respite care services in the state of Wisconsin. The primary goals of this study were to assess current awareness and perceptions of respite care services and to identify service needs and opportunities for improvement, with a focus on services for children from birth to 6 years old with behavioral or emotional disabilities.

The target audience for this research study consisted of social workers from Child Protective Services (CPS) in 72 counties in Wisconsin and directors of Head Start programs. To qualify for the study, all respondents must have indicated that they either personally refer clients or families to community resources or supervise staff members who make referrals.

## Methodology

An on-line survey instrument was utilized to collect the data for this study. The survey was available for respondents to complete between March 13, 2006, and May 5, 2006.

An e-mail invitation was sent to the target audience asking them to complete the survey by accessing a secure Web page on the Chamberlain Web site. A total of 124 invitations were sent—78 to contacts in Child Protective Services agencies and 46 to directors of Head Start programs.

During the initial fielding of the on-line study, early feedback from respondents prompted two changes to methodology. First, several contacts at Head Start programs indicated that they did not refer clients to community resources. As a result, they were no longer targeted in the research sample plan. Second, a number of county agency contacts indicated that they were not in a position to directly refer clients or families. Consequently, edits were made to the survey instrument to include respondents who supervised staff members who made referrals but did not directly refer clients or families to community resources.

Due to a lower participation rate than desired during the first two weeks of the study, Respite Care began networking within county agencies for additional contacts. During this networking, Respite Care discovered that the Department of Health and Family Services (DHFS) was conducting a lengthy, state-mandated census survey regarding child and family services, which was likely contributing to the low participation rate. At this point, Chamberlain recommended that the study be placed on hold until the conclusion of the DHFS study. On April 25, the study was resumed as follow-up e-mails were sent to those individuals who did not complete the survey upon receiving the first invitation.

Initial invitations were e-mailed to the newly acquired contacts received from Respite Care.

At the conclusion of the study, surveys were received from a total of 53 respondents representing 44 counties—41 full completes (36 from county agencies, 5 from Head Start) supplemented by 12 partial completes (11 county agencies, 1 Head Start).

**Margin of error**

Due to the small sample of Head Start agencies included in the study, results for this segment should be viewed as qualitative in nature only and are not included in the below calculations of margin of error.

For the county agency segment of the sample, since both fully and partially completed surveys were included in the data, the margin of error for this study varies by question according to how many respondents gave a response. Additionally, because survey respondents served the dual role of representing the universe of roughly 250 agency workers in attitudinal sections of the survey and representing one of 72 counties in sections of the survey related to awareness and usage of respite care services, the margin of error varies due to the difference in size between these populations.

Number of County Agents	Margin of Error	
	Attitudinal questions (Q1–Q3, Q19)	All other questions (Q4–Q18)
47 (full and partial completes)	±13.02%	±8.51%
36 (full completes only)	±15.33%	±11.71%

**Table 1. Variable Margin of Error**

As shown in Table 1 above, for the attitudinal sections of the survey in which a respondent relayed their personal opinions regarding respite care, the margin of error ranges from ±13.02% to ± 15.33%. In the sections of the survey related to awareness and usage of respite care services in a respondent’s county, the margin of error ranges from ±8.51% to ± 11.71%.

## Executive Summary

The perceptions of and associations with respite care offered by respondents were overwhelmingly positive. Respondents most commonly perceived respite care as short-term care for children that enables parents or caregivers to take a needed break from providing care. Respondents largely agreed with the positive value statements presented in the study, and only 8% of respondents expressed high levels of agreement with the statement that respite care “provides little value to my clients/contacts.”

Roughly two-thirds of respondents indicated that there were caregivers or families with children birth to 6 years old with behavioral or emotional disabilities who their agency did not refer to respite care services in the last 12 months. The primary explanation for not making these referrals was that caregivers cannot afford respite care services. Other reasons cited include a feeling that there is a lack of trusted respite care providers in the area and that a child’s disability does not receive government funding.

Presented with the hypothetical scenario that their agency had access to unlimited resources, 77% of respondents felt that the number of caregivers they referred to respite care would increase. The estimated number of additional referrals that would be made possible for the 34 counties accounted for in this study totals 1,317, of which 338 would be to caregivers of a child birth to 6 years old with behavioral or emotional disabilities. Should additional resources be made available to county agencies, their utilization of respite care services would undoubtedly be increased.

Respondents voiced a number of suggestions for improvement to respite care, the most frequently mentioned of which was more respite care providers. Other suggestions offered include more funding to pay for providers and more providers with the skills to deal with children with special needs.

Currently, the most common sources of information about respite care are referrals from co-workers, supervisors, and other agencies. This situation presents a distinct opportunity to heighten Respite Care’s outreach directly to county agencies and to enhance promotion of its statewide information and referral service.

# Detailed Findings

## Perceptions of Respite Care

Respondents were first asked to share what the term “respite care” meant to them. The associations and perceptions offered by respondents were overwhelmingly positive (see Table 2 below). Respondents most commonly perceived respite care as temporary or short-term care for children that allows parents or caregivers to take a needed break from providing care. Many respondents also stated that respite care helps to reduce the stress levels of parents and to decrease the likelihood of abuse and child neglect. Nineteen percent of respondents commented that respite care meant short-term care for those in need of a caregiver but did not specifically mention care for children. No respondents noted any negative associations or perceptions related to respite care.

<b>Comment (n=53)</b>	<b>Percentage</b>
Allows parents or caregivers to take a needed break	62%
Short-term care for children	59%
Helps reduce stress level of parents or caregivers	25%
Short-term care for those in need of a caregiver	19%
Lowers chances of abuse	13%
Lowers chances of child neglect	8%
Reduces out-of-home placements	6%
Helps improve the health of caregivers	6%
Reduces social isolation of caregivers	4%

**Table 2. Perceptions of Respite Care**

In addition to offering their unaided perceptions of respite care, respondents were asked to rate their level of agreement with a series of statements using a scale from 1 to 10, with 1 meaning completely disagree and 10 meaning completely agree. These attitudinal statements were designed to assess the perceived value of respite care among respondents.

Respondents largely agreed with the positive value statements presented in the study, as mean ratings ranged from a low of 6.80 for “reduces social isolation of caregivers” to a high of 8.73 for “allows family members to take a needed break.” Other highly rated statements included “helps reduce the stress level of caregivers,” with a mean of 8.61, and “reduces out-of-home placements,” with a mean of 8.08. For the most part, the relative mean scores for the statement ratings paralleled the relative frequencies of respondents’ verbatim comments displayed in Table 2. The only negatively positioned statement, “provides little value to my clients/contacts,” received a mean score of 2.20, with only 8% of respondents expressing high levels of agreement. Figures 1a and 1b (below) summarize the results of this section in terms of mean rating, percentage of

respondents in the top-three box (a rating of 8, 9, or 10), and percentage of respondents in the bottom-three box (a rating of 1, 2, or 3).

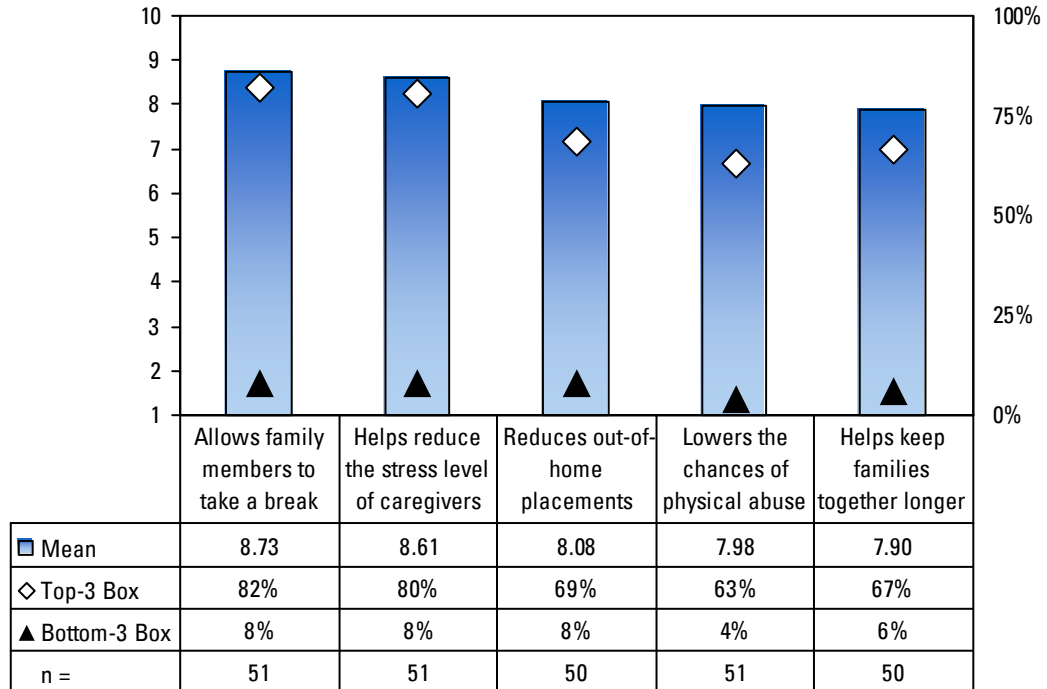


Figure 1a. Summary of Attitudinal Statement Ratings

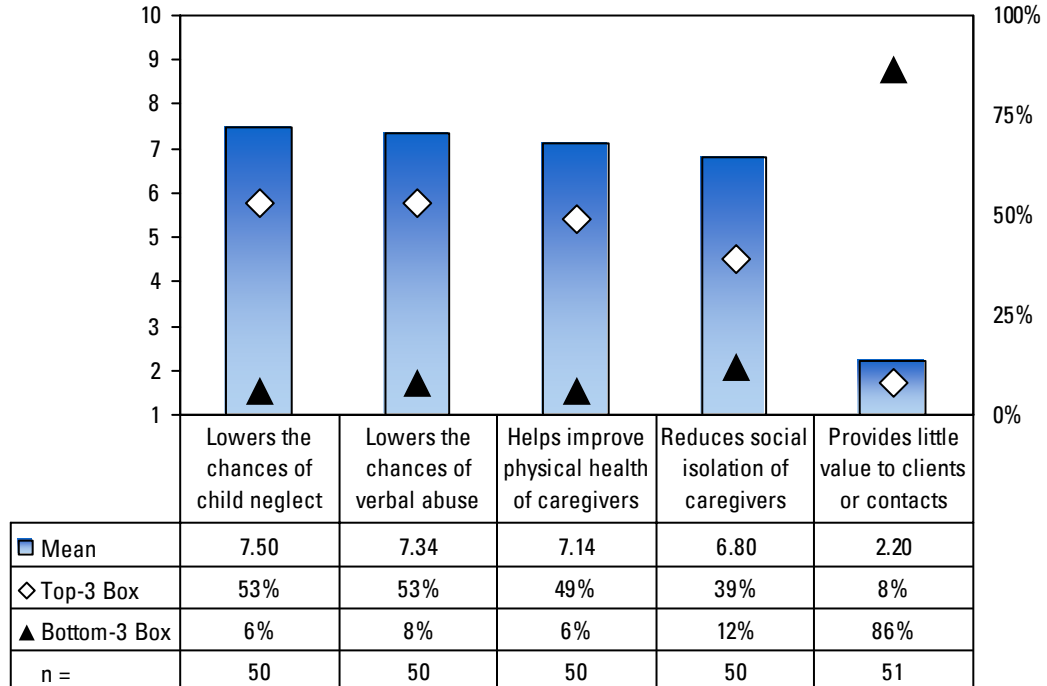


Figure 1b. Summary of Attitudinal Statement Ratings

Almost all respondents (98%) felt that respite care is best utilized by the caregivers or families providing care to children ages 7 to 12 (see Table 3 below). Very high percentages of respondents also felt that respite care is best utilized by the caregivers or families providing care to children birth to 6 years old (92%) and teenagers (88%). These results likely reflect that the nature of the work of the target audience is geared toward children. Fifty-nine percent of respondents felt that respite care is best utilized by the caregivers or families providing care to older adults.

Age Group (n=51)	Percentage
Children (7–12 years)	98%
Infants/Toddlers/Children (0–6 years)	92%
Teenagers (13–19 years)	88%
Older adults (60 years or more)	59%
Young adults (20–29 years)	47%
Adults (30–44 years)	47%
Middle-aged adults (45–59 years)	47%

**Table 3. Age Groups Whose Caregivers/Families Can Best Utilize Respite Care**

### **Awareness of Respite Care Services**

When asked to identify what respite care providers are available in their local area for caregivers and families with children birth to 6 years old, 71% of respondents indicated a family support coordinator in the county human services department and 61% indicated an independent contractor or individual who provides respite care services. An additional 6% of respondents mentioned United Cerebral Palsy. No other specific respite care providers were mentioned by more than one respondent. (For a complete list of providers mentioned, please consult the accompanying cross-tabs.)

Word-of-mouth is the source respondents most often rely on to obtain information about respite care services in their area (see Table 4 below). Fifty-seven percent of respondents reported that they obtain information via referrals from co-workers, 53% via referrals from another agency, and 43% via referrals from supervisors. Other commonly used sources of information about respite care services include respite care employee contact (cited by 37% of respondents), informational pamphlets (33%), and government listings (24%).

Source (n=51)	Percentage
Referrals from co-workers	57%
Referrals from another agency	53%
Referrals from supervisors	43%
Respite care employee contact	37%
Informational pamphlets	33%
Government listing	24%
Internet	16%

**Table 4. Top Sources Used to Obtain Information about Respite Care Services**

### **Usage of Respite Care Services**

In the last 12 months, 55% of respondents' agencies referred caregivers or families with children birth to 6 years old to a family support coordinator in the county human services department. Fifty-three percent of respondents' agencies have referred similar caregivers or families to an independent contractor or individual who provides respite care services. Twenty-six percent of respondents' agencies have made referrals to other respite care providers, though no specific providers were mentioned by more than one respondent.

Respondents have made referrals to caregivers and families of a wide variety of types of children in the last 12 months (see Table 5 below). The most commonly mentioned types of children whose caregivers were referred to respite care were behaviorally disabled (65% of respondents) and emotionally disabled (50%).

Classification of Child (n=46)	Percentage
Behaviorally disabled	65%
Emotionally disabled	50%
Cognitively disabled	44%
Physically abused	37%
Physically disabled	37%
Neglected	37%
Sexually abused	28%

**Table 5. Types of Children Whose Caregivers/Families were Referred to Respite Care within the Last 12 Months**

In addition to providing information regarding the different types of referrals their agencies have made, respondents reported estimates on the number of various types of referrals they have made in the last 12 months. Respondents were first asked broadly how many caregivers or families they have referred to a community respite care program or resource. Following up on that inquiry, respondents were asked to identify how many of those referrals were made to the caregivers of a child birth to 6 years old and how

many referrals among that subset included a child with behavioral or emotional disabilities. Results from this series of questions are summarized in Table 6 below and include the percentage of respondents falling in a given range as well as the mean and median number of referrals made for each set.

Number of Referrals (n=42)	All Referrals	Referrals to Caregivers of a Child Birth to 6 Years Old	Referrals to Caregivers of a Child Birth to 6 Years Old with Behavioral or Emotional Disabilities
0	26%	31%	36%
1-2	14%	26%	33%
3-10	29%	31%	24%
11-20	17%	7%	5%
21 or more	14%	5%	2%
Mean	11	5	4
Median	3	2	2

**Table 6. Referrals to Respite Care within Last 12 Months**

Sixty-four percent of respondents have made at least one referral to caregivers of a child birth to 6 years old with behavioral or emotional disabilities in the last 12 months, with a mean of four referrals made per respondent.

## **Respite Care Service Needs**

### **Referrals not made**

Respondents were asked to report the number of caregivers or families with children birth to 6 years old with behavioral or emotional disabilities that their agency did not refer to respite care services in the last 12 months. Roughly two-thirds of respondents indicated that there were such instances (see Table 7 below). The mean number of referrals not made to this population in the last 12 months was 14.

Number of Referrals (n=38)	Referrals to Caregivers of a Child Birth to 6 Years Old with Behavioral or Emotional Disabilities
0	34%
1-2	21%
3-10	24%
11-20	8%
21 or more	13%
Mean	14
Median	2

**Table 7. Referrals NOT Made to Respite Care within Last 12 Months**

The primary explanation for not making these referrals, noted by 44% of respondents, was that caregivers cannot afford respite care services. Other reasons cited include a feeling that there is a lack of trusted respite care providers in the area (26% of respondents), that a child’s disability does not receive government funding (30%), and that parents or caregivers do not follow through with referrals (33%). Table 8, below, displays the percentage of respondents who cited a given reason overall as well as the percentage of respondents who chose each reason when forced to select the one reason that most prevents this type of referral.

<b>Barrier to Referral (n=43)</b>	<b>Primary Barrier Percentage</b>	<b>Overall Percentage</b>
Caregivers cannot afford respite care services	33%	44%
You do not feel there are trusted respite care providers in the area	23%	26%
Child’s disability does not receive government funding	14%	30%
Parents or caregivers do not follow through with referrals	12%	33%
Respite care would not help the child’s situation	9%	21%
Parents or caregivers do not trust providers	7%	21%
There are language barriers between the child and respite care providers	2%	7%

**Table 8. Barriers to Referring More Caregivers of Birth to 6-year-olds with Behavioral or Emotional Disabilities to Respite Care**

Three respondents mentioned language barriers as reasons for not making more referrals to caregivers of children birth to 6 years old with behavioral or emotional disabilities. Spanish (3 respondents), Hmong (3), and Arabic (1) were cited as the languages with which there was a communication barrier.

**Optimal scenario**

Presented with the hypothetical scenario that their agency had access to unlimited resources, 77% of respondents felt that the number of caregivers they referred to respite care would increase. Twenty-three percent of respondents believed that the number of referrals would stay the same, while no respondents thought it would decrease.

Given the same assumption that their agency had unlimited resources to make all of the referrals that they thought appropriate for the members of their community, respondents were asked to estimate the number of various types of referrals they would make in an average 12-month period. This series of questions was phrased in the same manner as the series of questions that inquired about the usage of respite care services in the last 12 months and is presented in a similar fashion in Table 9 below.

Number of Referrals (n=38)	All Referrals	Referrals to Caregivers of a Child Birth to 6 Years Old	Referrals to Caregivers of a Child Birth to 6 Years Old with Behavioral or Emotional Disabilities
0	-	3%	5%
1-2	5%	11%	24%
3-10	34%	47%	47%
11-20	21%	16%	8%
21-50	21%	11%	8%
51 or more	18%	13%	8%
Mean	48	25	13
Median	15	7	4

**Table 9. Anticipated Referrals to Respite Care in an Average Year Assuming Unlimited Resources**

### Service opportunities

There were substantial increases in the number of all types of referrals that would be made in the aforementioned optimal scenario relative to the number that had been made in the last 12 months. For all referrals, the mean increased from 11 to 48. For referrals to caregivers of a child birth to 6 years old, the mean increased 5 to 25, and for referrals to caregivers of a child birth to 6 years old with behavioral or emotional disabilities, the mean increased from 4 to 13.

A more detailed examination of the data facilitates a county-specific representation of respite care service opportunities as displayed in Table 10 below. Subtracting the number of referrals made in the last 12 months from the number of referrals that would be made with unlimited resources for each county yields an approximate service gap in terms of the number of respite care referrals made. Respondents from Head Start programs representing multiple counties are excluded from this analysis for the purposes of consistency and simplification. Additionally, the following counties were excluded as they were not fully represented in the data collected for this portion of the study: Ashland, Bayfield, Brown, Burnett, Chippewa, Columbia, Dane, Dodge, Florence, Fond du Lac, Forest, Grant, Green, Green Lake, Iron, Jefferson, Juneau, Kewaunee, Langlade, Lincoln, Manitowoc, Marathon, Monroe, Oneida, Outagamie, Pepin, Polk, Racine, Rock, Rusk, Sawyer, Shawano, Taylor, Trempealeau, Vernon, Vilas, Waupaca, and Wood.

County	All Referrals			Referrals to Caregivers of a Child Birth to 6 Years Old			Referrals to Caregivers of a Child Birth to 6 Years Old with Behavioral or Emotional Disabilities		
	Within Last 12 Months	Anticipated in Average Year Assuming Unlimited Resources	Gap	Within Last 12 Months	Anticipated in Average Year Assuming Unlimited Resources	Gap	Within Last 12 Months	Anticipated in Average Year Assuming Unlimited Resources	Gap
Adams	0	40	40	0	10	10	0	10	10
Barron	0	10	10	0	8	8	0	3	3
Buffalo	15	45	30	7	30	23	4	10	6
Calumet	2	20	18	2	20	18	2	12	10
Clark	30	30	0	10	15	5	3	15	12
Crawford	12	25	13	5	10	5	1	4	3
Door	10	15	5	2	3	1	2	2	0
Douglas	3	3	0	3	3	0	2	2	0
Dunn	0	6	6	0	3	3	0	3	3
Eau Claire	30	200	170	20	90	70	20	80	60
Iowa	3	10	7	0	0	0	0	0	0
Jackson	1	15	14	1	7	6	1	7	6
Kenosha	50	100	50	25	75	50	20	75	55
La Crosse	20	200	180	8	100	92	8	50	42
Lafayette	3	12	9	3	7	4	2	6	4
Marinette	0	25	25	0	15	15	0	10	10
Marquette	0	6	6	0	6	6	0	4	4
Menominee*	5	8	3	4	7	3	4	5	1
Milwaukee	0	500	500	0	300	300	0	70	70
Oconto	5	12	7	5	12	7	4	4	0
Ozaukee	2	2	0	2	2	0	1	2	1
Pierce	0	5	5	0	3	3	0	1	1
Portage	100	125	25	40	60	20	40	40	0
Price	3	12	9	3	6	3	3	4	1
Richland	0	2	2	0	2	2	0	2	2
Saint Croix	20	75	55	5	35	30	2	5	3
Sauk	19	40	21	1	7	6	0	0	0
Sheboygan	1	6	5	1	6	5	0	6	6
Walworth	8	8	0	3	3	0	2	2	0
Washburn	2	4	2	0	2	2	0	2	2
Washington*	8	12	4	2	4	2	2	3	1
Waukesha	10	50	40	1	20	19	1	7	6
Waushara	11	25	14	6	12	6	3	8	5
Winnebago*	11	53	42	8	22	14	4	15	11
<b>Total</b>	<b>384</b>	<b>1,701</b>	<b>1,317</b>	<b>167</b>	<b>905</b>	<b>738</b>	<b>131</b>	<b>469</b>	<b>338</b>

\* For cases in which a county was represented by more than one fully completed survey, data displayed is an average of respondents' answers.

**Table 10. Service Gaps by County**

The overall service gap for these 34 counties represents a total of 1,317 referrals, 338 of which would be to caregivers of a child birth to 6 years old with behavioral or emotional disabilities. The largest service gaps (in absolute terms) for this subset of referrals were found in the counties of Milwaukee, Eau Claire, Kenosha, and La Crosse.

In addition to these notable service opportunities, respondents voiced a number of suggestions for improvement to respite care services in Wisconsin (see Table 11 below). The most frequently mentioned opportunity for improvement was more respite care providers, cited by 49% of respondents. Other suggestions offered included more funding to pay for providers (29% of respondents) and more providers with the skills to deal with children with special needs (20%). These comments echo respondents' feedback on the primary barriers to referring more caregivers of birth to 6-year-olds with behavioral or emotional disabilities to respite care.

Suggested Improvement (n=41)	Percentage
More providers	49%
More funding to pay for providers	29%
More providers with skills to deal with children with special needs	20%
Better, more training specific to respite care providers	15%
Improved accessibility to providers	7%
Improved communication regarding respite care options	5%

**Table 11. Improvements to Respite Care**

### **Respondent Profile**

The respondent pool for this study had the following demographic characteristics. (These statistics are representative of only the 41 respondents who completed surveys in their entirety, unless otherwise noted.)

- Seventy-one percent of respondents were female, and 29% of respondents were male.
- Twenty-seven percent of respondents were 55 years old or older. Twenty-four percent of respondents were 45 to 54 years old, 34% of respondents were 35 to 44 years old, and 15% of respondents were 25 to 34 years old.
- The majority of respondents (54%) were employed at an agency or program with 41 or more full-time employees. Twenty-nine percent of respondents reported having 31 to 40 full-time employees at their place of employment, 7% had 21 to 30 full-time employees at their place of employment, 7% had 11 to 20 full-time employees, and 2% had 10 or fewer full-time employees.
- Almost half of respondents had been employed in their field for 20 or more years, though a majority of respondents (71%) had been employed in their current position for 7 years or less. See Table 12 below for details.

Number of Years	In Your Field Percentage	In Current Position Percentage
Less than 2	5%	12%
2-4	2%	24%
5-7	5%	34%
8-10	12%	7%
11-13	5%	7%
14-16	15%	2%
17-19	7%	5%
20 or more	49%	7%

**Table 12. Years Employed**

- Seventy-two percent of all county agency respondents reported serving in the role of agency supervisor. The frequencies of other job responsibilities performed by county agency respondents are displayed below in Table 13.

Job Responsibility (n=47)	Percentage
Agency supervisor	72%
Intake	36%
Report writing	36%
Assessment	32%
Program manager	11%
Director	6%
Miscellaneous	6%

**Table 13. Job Responsibilities**