

# ONE-TIME RESPITE EVALUATION

## FISCAL YEAR 2015

### SUMMARY

- Fiscal Year 2015 was the second year the limited or one-time respite service program operated
- FY14 evaluation discovered significant decrease in caregiver stress and improved quality of life
- FY15 also discovered significant increase in quality of life for caregivers due to one-time respite
- Those that did not accept the service were significantly more likely to report less positive interactions and rating of State respite caseworker communication and knowledge
- Improvements requested include streamlining paperwork process, additional training on billing/how to use respite, more frequent communication with State respite caseworkers, and updated contact information for respite providers
- Overall, respondents reported it was a 'life saver' that helped keep the person receiving services in their home and out of care facilities

### INTRODUCTION

Since the 2013 general legislative session, Senate Bill 259 has allowed non-lapse funds to be used for one-time limited respite services for people waiting for ongoing services (Section 62A-5-102). Fiscal year (FY) 15 allocated between \$3,600 and \$5,000 for consumers to use throughout a 12-month period on respite services. This was the second year limited respite was offered. Because this service is still very new and subsequently has changed in practice since the first year, this evaluation was conducted to investigate the strengths and points of improvement for the FY15 cohort.

### RESEARCH OBJECTIVES

This purpose of this evaluation was to assess the quality of training materials, caseworker efficacy, caregiver ability to find providers for services, and determine overall strengths and weaknesses of the service.

#### *Research Questions*

1. What do caregivers think about the training materials provided in printed information packets and the strengthening families DVD?
2. Are there any predictors (demographic or otherwise) for who struggles the most with the paperwork process?
3. Do caregivers know about what State resource are available to help coach them through the paperwork process?
4. How are State respite caseworkers doing in terms of positive interactions, knowledge levels, and communication ability with caregivers?
5. Are there predictors for ability to find staff to provide respite services? Why are people having difficulty?

6. Are people using all of their funding? If no, would they like to extend their plan on a case by case basis?
7. What are the strengths and weaknesses of the service?
8. Did it improve the caregiver's overall quality of life?

## METHODOLOGY

This evaluation utilized a mixed method retrospective case study design that attempted to determine strengths and improvement areas for one-time respite services. The Division gathered data primarily through questionnaires sent in the mail to caregivers. All those that were selected for one-time respite services for the FY15 cohort were sent the questionnaire including those that did not use the service. Two questionnaires were developed, a long form for those who utilized the service and a short form for those who were selected but did not participate. The questionnaire primarily consisted of closed-ended Likert scale and open-ended attitudinal based questions. Data was analyzed largely using frequency counts, chi-square, and qualitative grouping.

Overall, 545 long form (service participants) and 394 short form (service non-participants) questionnaires were sent with an accompanying cover letter. Respondents returned a total of 337 usable surveys, 270 long forms and 67 short forms, within the month and a half collection period for a response rate of 37%. Four surveys were disqualified due to being less than 50% completed.

## RESULTS

### DEMOGRAPHICS

The majority of respondents were from Salt Lake, Utah, and Davis Counties; however, response percentages from both survey forms (participants and non-participants) were consistent with population weights across the state. This indicates a well-distributed study population and increases the generalizability of study results. The majority of respondents were between 35-54 years old (Participants: 57.09%, Non-Participants: 52.5%), female (Participants: 86.57%, Non-Participants: 86.25%), with an undergraduate degree or certificate (Participants: 39.47%, Non-Participants: 30.77%), and white or Caucasian (Participants: 85.82%, Non-Participants: 88.75%). Ethnic distribution of respondents was also fairly consistent with actual state percentages. Of the service participant respondents, 93% reported being the parent of the person selected for limited respite, while the remaining respondents were other family members/guardians, DCFS worker, and a landlord. Non-service participant respondents were also most likely to report being the parent of a person selected for respite services (85%), followed by other family members and foster parents. The majority of

respondents (Participants: 54.43%, Non-Participants: 51.4%) had waited for services for five or more years.

## SURVEY MEASURES:

### *Training Materials*

Participant respondents overall had positive feedback regarding the one-time respite program with some points of constructive criticism. The family training materials mandated by Utah Legislature was criticized by respondents as only being 'somewhat relevant or applicable' (51.95%) or 'not very relevant or applicable' (17.58%) compared to 30.47% reporting it being 'very relevant or applicable'. Respondents were also asked to explain how to improve the materials in an open-ended question, with many stating that they understood it was a type of 'hoop' to go through for the service; however, many respondents suggested that more training on how to bill and use billing codes, hiring staff, and best practices would be more beneficial to receive than family strengthening. Many respondents also stated that they did not feel it was relevant to their situation because of how severe their child's disability is and the video did not provide specific guidance on managing special needs. Others stated that although a DVD was fine to view, that it would be more convenient to have the training online with an online question form instead of a hard copy. This requirement for the one-time respite program is difficult because it is a legislative mandate, but providing optional training on other more relevant topics in addition to the strengthening families training or moving to an online platform (as suggested by respondents) may be helpful.

*What did you think of the training materials provided on the DVD?*

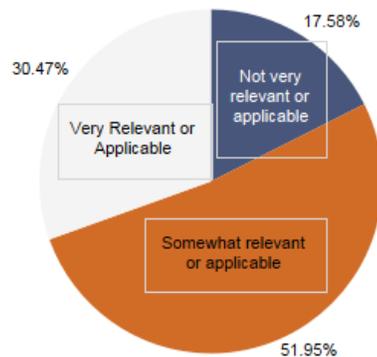


Chart 1. Training Material Attitudes, Long Form

### *Predictors & Caseworker Feedback*

Respondent demographics from each survey group (participants and non-participants) were not statistically different from one another. In addition, no demographic characteristics were found to

act as predictors in survey answers. Four relationships were discovered, however, that may provide insight to why people who did not utilize one-time respite services that were selected. Respondents that did not use the service were significantly more likely to be *unaware* that State workers are available to help them through the paperwork process than those that utilized the service ( $P=.0031$ ). This potentially suggests that not knowing about the option for additional help could possibly influence caretaker's decision to not complete the service process.

*Did you know there were workers at the State available to coach you through the respite paperwork process if you had questions or concerns?*

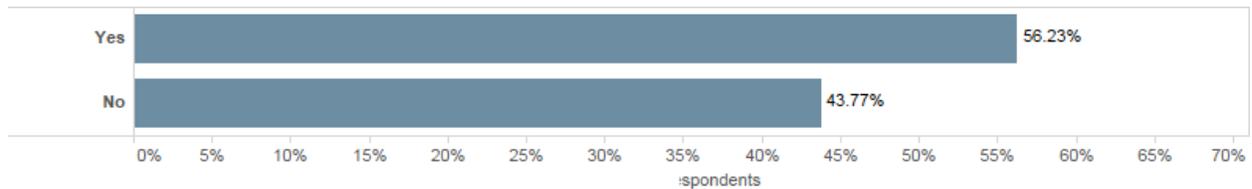


Chart 2. Paperwork Coaches; Long Form, Accepted Limited Respite

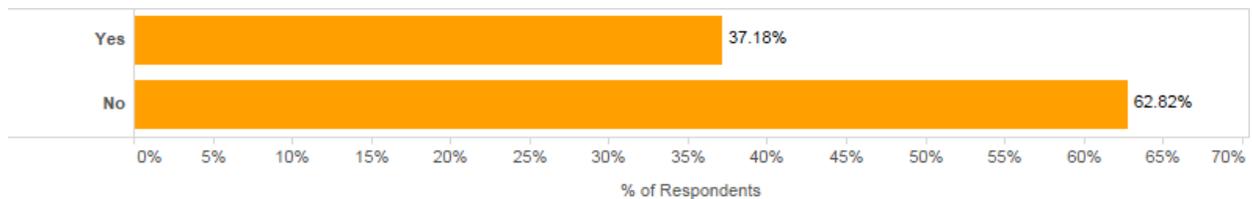


Chart 3. Paperwork Coaches; Short Form, Did Not Accept Limited Respite

Additionally, those that did not use the respite services were also significantly more likely to report having only 'fair' or 'good' interactions with respite caseworkers compared to service users, who most commonly reported 'good' or 'very good' interactions ( $p<.0001$ ).

*How would you rate the interactions with your State respite caseworker?*

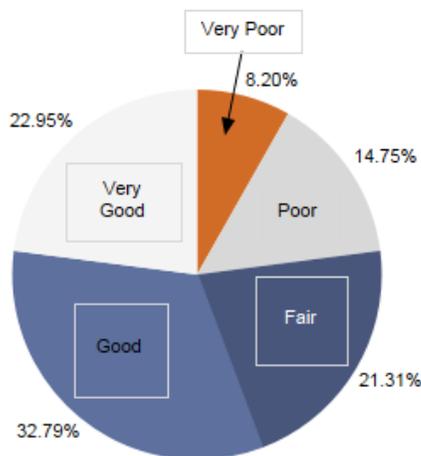


Chart 4. Interactions; Short Form, Did Not Accept Limited Respite

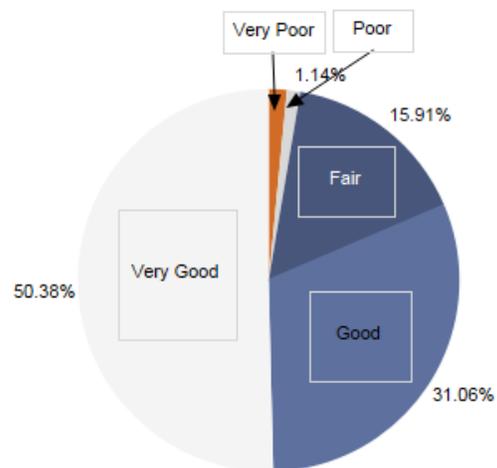


Chart 5. Interactions; Long Form, Accepted Limited Respite

Respondents that did not receive limited respite were also significantly more likely to report lower rating of their respite caseworker’s knowledge ( $P < .0001$ ). Similarly, those that did not receive the service were significantly more likely to rate the State caseworker’s communication at lower levels than the service users ( $P = .0002$ ). This could also indicate that negative experiences or perceptions of the State caseworker’s influences caregiver decision to sign up for the service or not (see Appendix A for table of survey responses).

*How would you rate the State respite caseworker’s communication? Including if they responded to emails or calls in a timely and effective manner.*

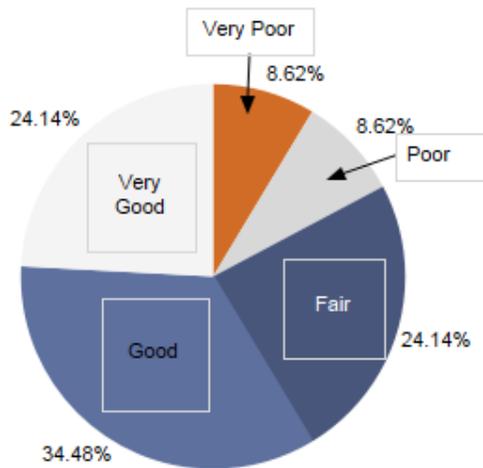


Chart 6. Communication; Short Form, Did Not Accept Limited Respite

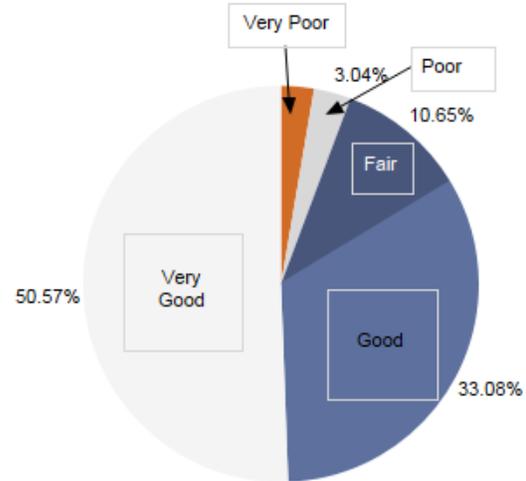


Chart 7. Communication; Long Form, Accepted Limited Respite

*How would you rate the knowledge of your State respite caseworker who assisted you through the respite services process?*

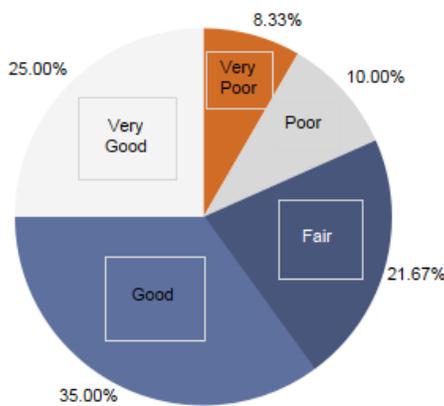


Chart 8. Knowledge, Short Form, Did Not Accept

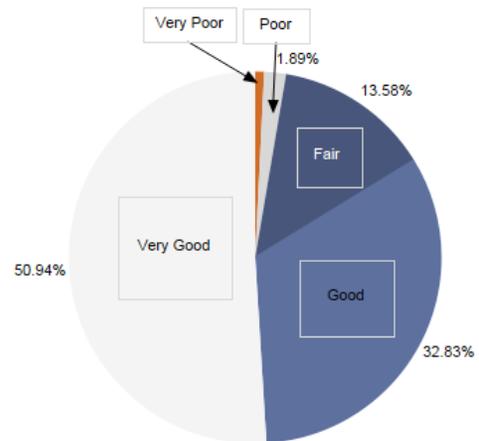


Chart 9. Knowledge, Long Form, Accepted Limited Respite

## Respite Services & Staffing

The ability to find staff for those that utilized the service varied widely. In fact, responses were nearly equal in distribution.

*How would you rate your ability to find staff to provide Respite services?*

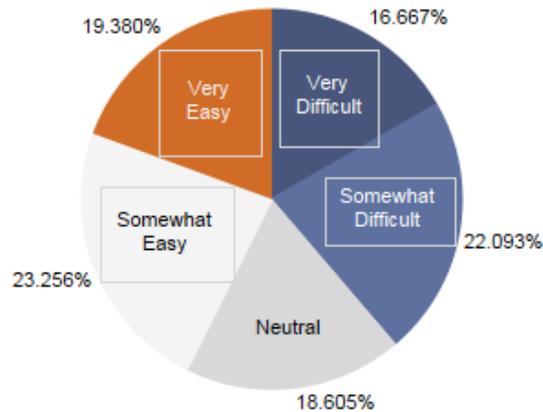


Chart 10. Staff Ability; Long Form, Accepted Limited Respite

Those that did experience difficulty finding a provider most commonly reported (1) they had a hard time knowing where to start, (2) the consumer's disability was so severe, caregivers reported that the providers refused to take them on, (3) the service providers were limited in their county (Salt Lake and rural counties most common), (4) the caregiver did not trust providers to take care of the person receiving services so they used family, (5) the list of providers given by the State was not accurate, (6) pay is too low to attract high-quality staff and high turnover makes it difficult for the consumer, and (7) the consumer was under 18 and the caregiver could not find a respite provider that accepted children. Respondents reported a desire to have an updated list of providers and a guidance sheet or training on how to find and hire staff.

The majority of respondents also reported that they did not use all of their allotted funding during the 12-month cycle (57.7%) and wished they could have extended their plan (69.5%). Many respondents stated that they were confused about how much time they had, and were saving the funding for summer months. Others reported that it took them a while to find and hire providers, which reduced the amount of time they had to actually use the funds.

### Service Strengths

Overall, caregivers reported that using the limited respite services helped meet their immediate needs and significantly improved their quality of life ( $P=.0001$ ). Respondents also reported that they were very happy with the services the State caseworkers provided, and that they “could have questions answered with a phone call” and that they were always “quick to respond”.

Survey Responses	Service Participants		Rao Scott Chi	Non-Participants	
<b>Did the respite services help meet your immediate needs?</b>	N	%	P<.0001	N	%
No	12	4.60%		-	-
Mostly	77	29.50%		-	-
Yes	<b>172</b>	<b>65.90%</b>		-	-
<b>One-Time Respite services improved my overall quality of life.</b>	N	%	P<.0001	N	%
Strongly Disagree	12	4.69%		-	-
Disagree	2	0.80%		-	-
Neutral	17	6.64%		-	-
Agree	85	33.20%		-	-
Strongly Agree	<b>140</b>	<b>54.69%</b>		-	-

Table 1. Select Survey Responses

Many caregivers also reported that the service provided a much-needed break and helped strengthen the parent relationship and/or allowed for more hours at work. One respondent said, “being a single parent with a seriously handicapped [child], the services allowed me to help with his needs and care when I had to travel on business with my work. It was a life saver”. Others reported that the service allowed them to schedule their own medical appointments and run errands much easier than without the service, which alleviated stress and improved health. Another respondent reported that it also was a very positive experience for their child, that “having someone work with my [child] on occupational therapy exercises, exercising, socializing; this has been a huge blessing because it gives my [child] something to look forward to and it gives me a much needed break”. This service also helped parents avoid burn-out, which can help keep people with disabilities in the State of Utah in their homes and communities and out of institutions. One respondent said, “it really helps caregivers get a break from 24/7 care they give. Without respite, I would have had a nervous breakdown. I did not receive respite this time around and have had to put my child in an ICF/ID facility”. This is important because, with respite, this caregiver was able to mentally handle providing daily care for their child; however, upon losing the services, they felt it was necessary to place the child in a care facility. This indicates that

limited respite services help promote the Division's goal of keeping people with disabilities out of institutions and in their communities.

### *Service Improvements*

Caregivers largely had positive feedback about how this service improved their quality of life; however, there were a few points of constructive feedback for improvement. The most common responses were:

1. Improve communication by ensuring information is clear, consistent, and timely
2. Allow caregivers to use the funding until it is depleted without a time limit
3. Improve training on how to use respite, including how to find staff, manage timesheets, and bill for services
4. Update provider lists to be more accurate and include those that cover children, which do in-home services, and individuals that can provide care outside of formal providers
5. Send periodic communication (via email or mail) to check in and provide contact information of who to reach out to for help during paperwork process
6. Streamline paperwork and training process as much as possible

## CONCLUSION

One time respite services are designed to help alleviate some of the burden that caregivers of people with disabilities experience by providing respite while they wait for ongoing services. This evaluation discovered that this is being accomplished with largely positive results. Receiving this service has helped caregivers with mental and physical health, financial opportunity, and improving family relations. It has also helped keep people with disabilities receiving care to stay in their homes by providing assistance to the caregivers. This evaluation also discovered that those who were selected for this service but did not utilize it did not have as positive experiences with respite caseworkers or know about resources to help them through the process. It also highlighted that although there are some points for improvement, it has largely been a successful program with high-quality employees.

APPENDIX A

<b>Table 2. Summary of Survey Responses</b>	<b>Long Form</b>		<b>Short Form</b>		<b>Rao-Scott Chi</b>
<b>How would you rate the paperwork process?</b>	N	%	N	%	P=.2275
Very Difficult	38	14.56%	9	12.16%	
Somewhat Difficult	<b>102</b>	<b>39.08%</b>	<b>26</b>	<b>35.14%</b>	
Neutral	<b>80</b>	<b>30.65%</b>	<b>26</b>	<b>35.14%</b>	
Somewhat Easy	29	11.11%	5	6.76%	
Very Easy	12	4.60%	8	10.81%	
<b>Did you know there were workers at the State available to coach you through the respite paperwork process if you had questions or concerns?</b>	N	%	N	%	<b>P=.0031</b>
No	<b>116</b>	<b>43.77%</b>	<b>49</b>	<b>62.82%</b>	
Yes	<b>149</b>	<b>56.23%</b>	29	37.18%	
<b>What did you think of the training materials provided on the DVD?</b>	N	%	N	%	
Not Very Relevant or Applicable	45	17.58%	-	-	
Somewhat Relevant or Applicable	<b>133</b>	<b>51.95%</b>	-	-	
Very Relevant or Applicable	78	30.47%	-	-	
<b>How would you rate the knowledge of your State respite caseworker who assisted you through the respite services process?</b>	N	%	N	%	<b>P&lt;.0001</b>
Very Poor	2	0.75%	5	8.33%	
Poor	5	1.89%	6	10.00%	
Fair	36	13.58%	13	21.67%	
Good	<b>87</b>	<b>32.83%</b>	<b>21</b>	<b>35.00%</b>	
Very Good	<b>135</b>	<b>50.94%</b>	15	25.00%	
<b>How would you rate the interactions with your State respite caseworker (Nadya or Brianna)?</b>	N	%	N	%	<b>P&lt;.0001</b>
Very Poor	4	1.52%	5	8.20%	
Poor	3	1.14%	9	14.75%	
Fair	42	15.91%	<b>13</b>	<b>21.31%</b>	
Good	82	31.06%	<b>20</b>	<b>32.79%</b>	
Very Good	<b>133</b>	<b>50.38%</b>	14	22.95%	
<b>How would you rate the State respite caseworker's communication? Including if they responded to emails or calls in a timely and effective manner.</b>	N	%	N	%	<b>P=.0002</b>
Very Poor	7	2.66%	5	8.62%	
Poor	8	3.04%	5	8.62%	
Fair	28	10.65%	<b>14</b>	<b>24.14%</b>	
Good	87	33.08%	<b>20</b>	<b>34.48%</b>	
Very Good	<b>133</b>	<b>50.57%</b>	<b>14</b>	<b>24.14%</b>	

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