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Independent living program evaluation for Rebuilding All Goals Efficiently

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Abstract

This paper evaluates the outcome of independent living (IL) services provided to clients with Spinal Cord Injuries (SCI) by a local non-profit organization, Rebuilding All Goals Efficiently (RAGE). Agency services are directed at increasing client self-sufficiency, self-advocacy, and maintenance of least restrictive living environment. Secondary data provided by RAGE for 22 SCI clients who received services in FY10 was used in the evaluation. Outcomes were measured for living arrangement at case closure, impact of services on client's life, and cost effectiveness of services provided. Descriptive statistical analysis of the data revealed successful outcomes for all 22 SCI clients. All clients reported a decrease in functional limitation allowing them to maintain or attain the least restrictive living arrangement following provision of services. Service costs were higher for clients with 0-14 years post disability onset indicating that services were provided to the clients with the most need, either at onset of injury or to upgrade services. The report includes short and long-term recommendations to the agency for service delivery enhancement and improvement in data collection for future studies.

Keywords: independent living, community integration, least restrictive living environment

Table of Contents

Introduction 4

Historical Background 5

Agency Background 6

IL Program 7

Program Delivery 8

Performance Monitoring 10

Purpose of Evaluation 11

Data Collection 12

Data Analysis 13

Demographics 13

Program Outcomes 15

Conclusion 21

Limitations 21

Recommendations 23

Acknowledgements 24

References 25

Appendices ..... attached as separate document

Introduction

Research has shown that living environment and level of independence play a significant role in quality of life for individuals with spinal cord injury (SCI) (Augutis, et al., 2007). SCI is defined as "an insult to the spinal cord resulting in a change, either temporary or permanent, in its normal motor, sensory, or automatic function" (Dawodu, et al., 2011). Specifically, restrictions experienced in institutional living are known to have a diminishing effect on happiness, health, and lifespan for those experiencing such challenges (Augutis, et al., 2007). In addition to detrimental physical, physiological, and psychological effects, institutionalization is a costly health care expense to the public and private sector (SCI Facts & Statistics, 2011). Literature supports that institutionalization should be the last resort for those with SCI if society is to maintain a standard of dignity and choices for such individuals (Augutis, et al., 2007).

Subsequently, a variety of resources and services have evolved over the last 40 years to assist challenged individuals in maintaining the least restrictive environment possible and improving their self-sufficiency level and quality of life (Karger & Rose, 2010). These programs are generically termed Independent Living or "IL" services and cover a gamut of supports from case management to in-home attendant care, adaptive devices, and modifications for individuals experiencing limitations (Simpson, 1999).

This project examines the outcomes of such IL supports by evaluating a program known as Rebuilding All Goals Efficiently (RAGE). The University of Nevada Las Vegas (UNLV) Master of Public Administration (MPA) students performing the evaluation included the following data collection methods:

- Interviews with RAGE Executive Director and Director of Program Development;

- Analysis of client program records;
- Analysis of client data both from RAGE and the Nevada Aging and Disability Services Division (ADSD);
- Literature review; and
- Analysis of national statistical data from professional and governmental websites.

The IL program will be assessed on its supports specifically to individuals with SCI as a subgroup within the agency's general service population. Service outcomes will be evaluated on:

- Ability to maintain or attain the least restrictive environment.
- The impact of the services provided on the client's functionality and subsequent quality of life.
- Cost effectiveness of services rendered.

The results of the evaluation and accompanying conclusions are summarized and include recommendations to the RAGE agency for usage in future program planning and service delivery improvement.

Historical Background

The Rehabilitation Act of 1973 (Rehabilitation Act) is the federal mandate that prohibits the discrimination of disabled individuals. Title VII of the Rehabilitation Act is designed to promote independent living and community integration by providing guidance and federal funding for state IL programs (United States Access Board, n.d.). State laws are written to complement the requirements of the Rehabilitation Act. Nevada IL programs are operated under mandates listed in Nevada Revised Statues (NRS) 426 and 427A and Nevada Administrative Code (NAC) 427A (Nevada Legislature: Law Library, 2011). These mandates provide the

infrastructure for provision of IL services to individuals with disabilities, including qualifying conditions, program monitoring, regulation for service delivery, and basis for funding. Additionally, the passage of the Olmstead Act in 1999 further enforced the rights of disabled individuals to protection from "unjustified institutionalization" and "unlawful discrimination" (HHS, n.d.).

RAGE is monitored by the ADSD for fiscal and programmatic oversight. The mission of its IL program is to provide community "resources that promote equal opportunity and life choices for people with disabilities, through which they may live independently in the community of their choice and control their lives" (ADSD, 2007, p. 8). As a state-designated provider, RAGE receives program funding from state and federal sources in addition to grants. State funding is provided under NRS 426, 427A, and NAC 427; federal funding is provided under Title VII of the Rehabilitation Act. State statutes identify criteria for federal fund matching. Federal funding is used to supplement state funding; however, the state is tasked with overseeing and distributing both levels. State funding may be used only for direct services to clients. Federal funding may be utilized for administrative overhead. RAGE also receives grant awards from Ameristar Casinos and the Craig H. Neilsen Foundation.

Agency Background

RAGE is a 501(c) 3 nonprofit agency dedicated to assisting seniors and disabled individuals in Southern Nevada. The agency was founded in 2005 by Reggie Bennett, a long-time advocate for the disabled community. Its mission is "to provide a higher quality of life to people with disabilities by empowering them to judge, direct and manage the services they need" (RAGE, n.d.). The agency's objective is to enhance the lives of clients by increasing their abilities and independence, thereby reducing their risk of institutionalization. RAGE's

philosophy is to “educate clients about being self-reliant and [facilitating] their efforts to achieve self-sufficiency and independence in the home and community” (RAGE, n.d.).

The agency provides a complete service array that supports disabled individuals to maintain their independence and advocate for their needs. All programs offered are directed at empowering clients in managing their own lives. RAGE programs include: Independent Living program, Working for Independence program, Spinal Cord Injury Network, and Fitness Mentoring. The wide range of services offered by RAGE exemplifies a well-rounded program that is designed to helping clients meet their potential combined with a committed staff to address their personalized needs.

IL Program

The focus of this evaluation is RAGE’s IL program, which provides financial assistance to severely disabled individuals in order to facilitate independence and community integration (RAGE, n.d.). The primary goal of the program is to improve the quality of life for clients by helping them regain their autonomy, keeping them in the community and out of institutions. IL is the agency’s third largest program, providing home and vehicle modifications, and includes assistive technology services to improve mobility. Home modifications include roll-in showers, grab bars, ramps, doorway widening, and stair lifts. Vehicle modifications include wheelchair lifts, hand controls, and seat transfers. Assistive technology services include computer and other mobility training devices. These modifications and services not only assist RAGE clients, but can also alleviate some of the burden on caregivers - physically, emotionally, and financially.

RAGE operates as the program of “last resort” and eligibility requirements necessitate that clients have exhausted all other resources. Many clients are enrolled through referrals from

other service agencies or from former RAGE clients. Prospective IL clients must meet the following requirements:

- Must reside in Nevada and have a severe disability with a limitation in their ability to function independently.
- Must have an expectation that services will improve applicant's functional independence.
- Income qualification is based on income level, with a sliding scale policy in place to help low-income clients. Some applicants are asked to share in the costs.
- If applicant qualifies for other programs, those resources must be used first (RAGE, 2011).

Program Delivery

The IL program is administered utilizing a client-driven approach, in which the case manager and client work together to determine needs and a service plan. This relationship continues through service implementation and follow-up. Services include the development of the client's self-advocacy and self-sufficiency skills through counseling, education, and access to resources. To summarize, IL clients are guided in the following:

- Development of a plan to ensure maximized independence;
- Identification of public and private resources (including the IL program) to secure needed services;
- Choice of vendors for modifications and other needs;
- Provide feedback on program assistance, allowing program to expand and more effectively address client needs; and
- Becoming effective self-advocates (RAGE, n.d.).

Screening and intake. Applicants are pre-screened by an Intake Coordinator to ensure they meet the minimum eligibility requirements. If they do not meet these, they are provided referrals to other service agencies. Qualified applicants are assigned an Independent Living/Aging and Disability Resource Specialist (hereinafter referred to as the "Specialist"), who serves as a case manager and guides them through a comprehensive application process (Bennett, R. & Graham, C., personal communication, May 25, 2011) (Appendix A). This includes gathering client demographic information and medical background to ensure eligibility documents are on file.

The Specialist works with the client and/or medical personnel, including physicians and physical/occupational therapists, to conduct a needs assessment and develop the aforementioned service plan. The plan is then reviewed and approved by the Executive Director before the modifications recommended can be provided. In instances where modification costs exceed the financial cap, ADSD approval is required to proceed. Clients then share responsibility in implementing the service plan in conjunction with the Specialist (Bennett, R. & Graham, C., personal communication, May 25, 2011).

Case management. Case management services are provided through completion of the service plan and with mutual agreement of the client. Specialists are responsible for:

- Ensuring services are provided;
- Monitoring and evaluating services;
- Identifying financial resources;
- Coordinating vendor services;
- Developing and implementing the service plan;
- Documenting client information;

- Referring clients to other agencies offering relevant services; and
- Case closure.

Upon service completion, the Specialist will follow-up with the client to determine if all needs and goals identified in the plan have been achieved prior to case closure. Once the case is closed, clients are provided with a follow-up survey to complete and send to the ADSD (Appendix B). These surveys provide information on the client's levels of satisfaction, service impact, living arrangement, use of the modification and level of self-care. Follow-up contact is then maintained by the Specialist to ensure client is maintaining self-sufficiency.

Performance Monitoring

IL program performance is tracked by RAGE with oversight by ADSD. Client records are maintained in an electronic environment which allows for real-time access to program performance and client outcomes data. RAGE is required to complete state grant reporting forms, input data into the Social Assistance Monitoring Software (SAMS) program, and provide client satisfaction follow-up surveys (Bennett, R.; Graham, C.; & Pasquale, C., personal communication, April 13, 2011). RAGE submits monitoring reports at the end of each fiscal year to ADSD. These reports include the following information:

- Number of clients served;
- Target populations served;
- Client satisfaction, including ratings for staff, outside vendors, choice and control, overall satisfaction, program impacts; and
- Number of outreach programs.

According to the FY10 Annual Performance Report for State Independent Living Services Program, "all grantees undergo a fiscal review by a Certified Public Accountant, as well

as monitoring by an independent evaluator. Individual case evaluations are conducted through case file reviews and in-person client interviews by an independent entity contracted by the DSU" (ADSD, n.d. p. 5). ADSD, as a Designated State Unit (DSU), performs an annual audit of the program for compliance. The state agency utilizes a standardized reporting format published by the United States Department of Education. ADSD then submits a written report of its findings on RAGE's performance measures and client satisfaction ratings (Appendix C). Continued passage of performance measures and client satisfaction ratings are required for RAGE to maintain their grant status.

Additionally, RAGE inputs the following information into the SAMS electronic database (Appendix D):

- Goal areas set and whether the goals were met (domains include Communication, Mobility/Transportation, Community Services, Self-Care, and Other);
- Limitation Ratings before and after service on a scale from 1-10 Levels of self-care (10 goal areas);
- Final living arrangement at time of closure;
- Actual cost of services;
- Services rendered to the client; and
- Date of case closure.

Purpose of Evaluation

UNLV MPA students consulted with the RAGE agency and determined that the focus of the evaluation would be the Independent Living (IL) program. RAGE Executive Director Reggie Bennett and Director of Program Development Celeste Graham suggested that the

students perform an evaluation of outcomes for a subset of IL clients. The subset selected were SCI clients who were provided services in FY10.

Successful outcomes for clients of the RAGE IL program are demonstrated in the ADSD survey data provided by the agency. ADSD FY10 survey data reveals that overall client satisfaction with the IL program was rated as very good to excellent by 93.1 percent of the clients surveyed. This rating exceeded the State grant objectives performance standard of 90 percent. According to the survey, "the overall quality of life improved a lot or quite a bit" for 77.8 percent of the FY10 clients following provision of services. (Appendix C).

Evaluation of the SCI clients recommended by the RAGE Executive Director will provide information on program outcomes for a diverse subset of clients with varying types of limitations, service needs, age of disability onset, and level of injury. The ADSD grant monitoring data does not include information on the actual cost of services provided to each client by RAGE nor identify trends associated with a decrease in the client's limitation rating. The internal data provided by RAGE will include this information and will be utilized in the evaluation.

Data Collection

According to ADSD grant monitor, John Rosenlund, RAGE closed 178 IL cases in FY10 (Rosenlund, J., personal communication, June 10, 2011). RAGE provided an Excel spreadsheet containing internal data collected for 36 SCI clients whose cases were closed in FY10 for use by the evaluation team. Of the 36 clients, 14 did not receive RAGE services and were therefore filtered out of the dataset. Appendix E provides background and service results on selected SCI clients.

The evaluation team identified three data indicators in the dataset that would be used to perform a descriptive statistical analysis of program outcomes. Additional demographic information on the 22 SCI clients was also included in the data analysis. (Appendix F)

Data Analysis

The following data indicators were used to evaluate the outcomes of the IL program for SCI clients:

- Ability to maintain or attain the least restrictive environment. There was a comparison of the living arrangement at the start of the program and at case closure.
- The impact of the services on the client's life. The mean percent decrease in the functional limitation rating was calculated from the start of provision of services to case closure.
- Cost effectiveness of services rendered. Evaluated using descriptive statistics for the actual cost of services provided, years post disability onset and mean percent decrease in functional limitation rating.

Demographics

Gender. According to the National Spinal Cord Injury Statistical Center (NSCISC), there are a higher percentage of spinal cord injuries (80.7%) that occurs in males (NSCISC, n.d.). The FY10 SCI data also correlates with a higher percentage of males who were provided services by RAGE (Table 1).

Table 1: Gender of RAGE's SCI clients for FY10

Gender			
n (%)	Male	Female	Total
Total	13 (59)	9 (41)	22

Race. The NSCISC reports a trend over time in the "racial/ethnic distribution of persons in the database. Among persons injured between 1973 and 1979, 76.8% were Caucasian, 14.2% were African American and 0.9% were Asian. However among those injured since 2005, 66.5% are Caucasian, 26.8% are African American and 2.0% are Asian" (NSCISC, 2011, p. 12). The racial distribution for the FY10 SCI clients correlates with the national statistics from NSCISC (Table 2).

Table 2: Race of RAGE's FY10 SCI clients

Race					
n (%)	Caucasian	African American	Hispanic	Hawaiian	Total
Total	16 (72)	4 (18)	1 (5)	1 (5)	22

Age. The NSCISC reports that the average age of injury for SCI was 28.7 years from 1973 to 1979 with most injuries occurring between the ages of 16 and 30. "However, as the median age of the general population of the United States has increased by approximately 9 years since the mid-1970, the average age of injury has steadily increased over time. Since 2005, the average age of injury is 40.7 years" (NSCISC, n.d.). The average age at injury of the SCI clients was 31 years with a minimum age of 11 years and maximum age of 57 years.

Program Outcomes

Ability to attain or maintain least restrictive environment. The NSCISC reports that "overall, 89.8% of persons with SCI who are discharged alive from the system are sent to a private, non-institutional residence (in most cases their homes before injury). Only 6.2% are discharged to nursing homes. The remaining are discharged to hospitals, group living situations or other destinations" (NSCISC, n.d.). The philosophy of the RAGE program is to facilitate the client's efforts to achieve self-sufficiency. Clients are asked to report their living arrangement (dependent, independent, or assisted) at the start of the program and when the case is closed. Data provided by RAGE included this information.

For the data analysis, clients who reported the same living arrangement at the start of the program and case closure were included in the "maintain" grouping. Clients who reported a change from dependent to independent were included in the "attain" grouping. Clients who reported moving to an institution or moving from an "independent to dependent" living arrangement were included in the "assisted" grouping. Analysis of the RAGE SCI data revealed that 91 percent (20/22) of the clients attained or maintained the least restrictive living environment following the provision of services by RAGE (Figure 1).

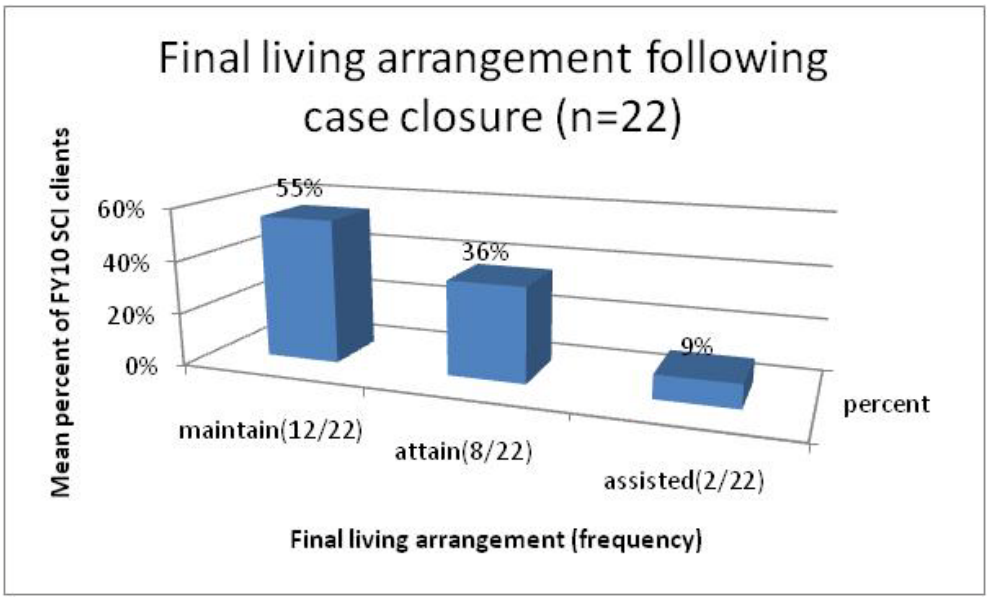

Figure 1: Final Living Arrangement for FY10 SCI clients

Impact of services provided on client's life. During the needs assessment process, each client, in conjunction with the Specialist, identifies the type of functional limitation for which they are requesting services. Each limitation type may involve multiple goal areas. The 5 categories of functional limitations include: Communication, Mobility/Transportation, Community Services, Self-Care and Other (Home access for the FY10 SCI clients). Mobility/transportation services could include installation of van modifications, purchase of wheel chairs, scooters or portable ramps. Self care services could include home modifications such as roll in showers or installation grab bars. Figure 2 depicts the frequency of each of the functional limitation types in the FY10 SCI dataset.

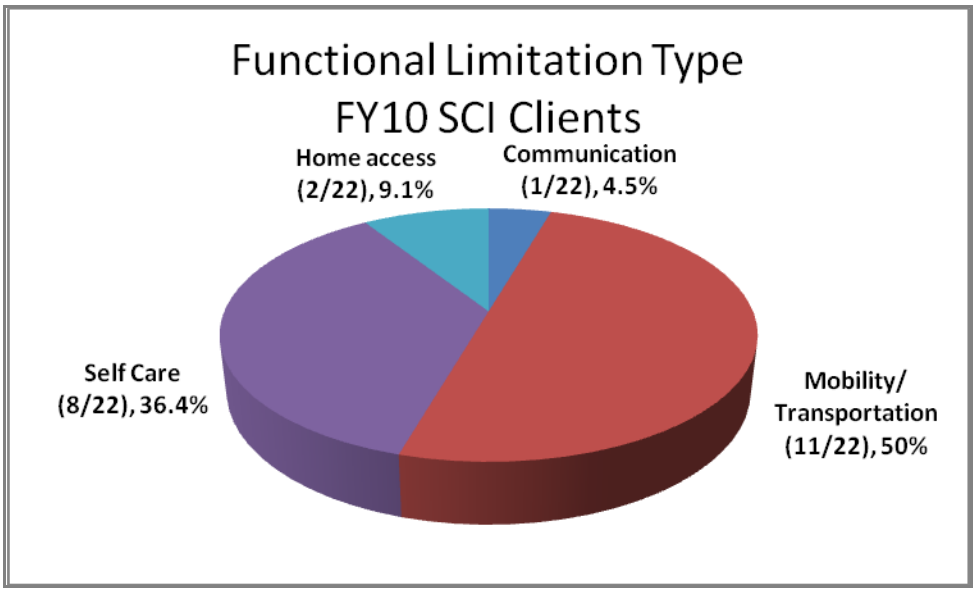

Figure 2: Functional limitation type frequency for FY10 SCI clients

During the needs assessment intake process, each client identifies goals that would help them attain further self-sufficiency. Ten different goal areas may be chosen and each client may identify multiple goals. The goal areas include: Community Services, Information Access/Technology, Self-Care, Educational, Personal Resource Management, Communications, Vocational, Mobility/Transportation, Self-Advocacy/Empowerment, and Other (Appendix A). Before the services are provided, the client rates their current functional limitation of each goal using a scale of 1 (not limited) to 10 (very limited). Following provision of services and case closure, each client is asked to again rate the limitation of each goal using the same scale. Both ratings are subjective. The goal rating data is then entered into the RAGE electronic database and was included in the FY10 SCI dataset.

On a scale of 1-10, all 22 of the SCI clients rated the severity of their limitation as a 10 prior to the provision of services. The difference in the pre and post service limitation rating was used to calculate the mean percent decrease in functional limitation severity for the SCI clients. If multiple goals for each client were identified, the goal rating differences were averaged so that

each client received one final percent decrease in the limitation for RAGE services. A higher percent decrease in functional limitation would indicate that the services provided to the client were more successful in fulfilling the goal identified during the needs assessment. The arithmetic mean (average) of each client's functional limitation decrease was grouped into four different categories (0-25%, 26-50%, 51-75% and 76-100%). The categories were mutually exclusive and exhaustive, i.e. every case could be classified in one and only one category. The frequency of the percent decrease in limitation following case closure is provided in Figure 3.

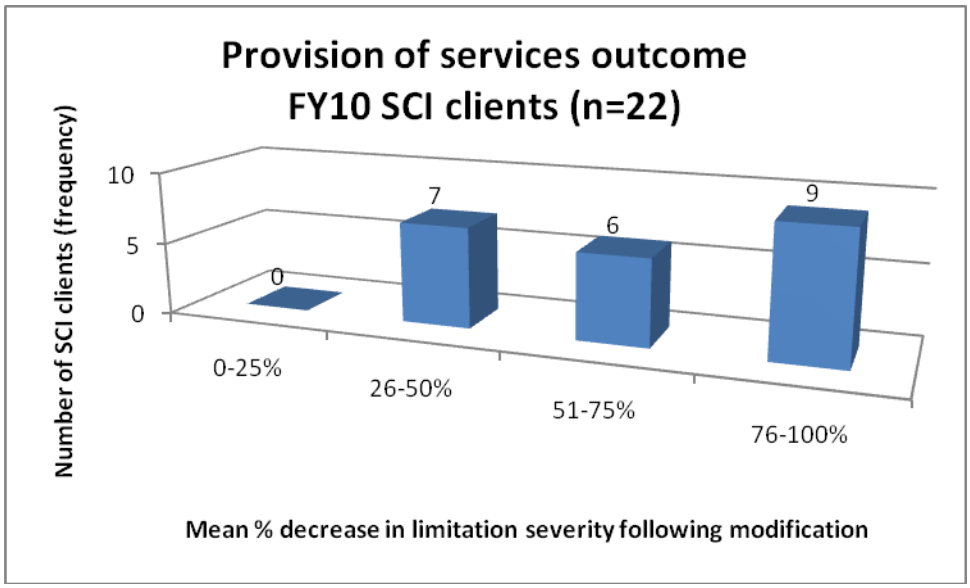

Figure 3: Percent decrease in limitation following case closure for FY10 SCI clients
Note: Mean % decrease in limitation FY10 SCI clients (n= 22)

For 100 percent of the SCI clients, a >25% decrease in the severity of their limitation was reported. For 40 percent (9/22) of the SCI clients there was a > 75% decrease in the severity of limitation. These percentages would indicate that the services provided by RAGE resulted in a positive outcome for the client.

Cost effectiveness of services provided. The dataset included the actual cost of the services provided to the 22 SCI clients. Descriptive statistics for the actual cost of the services provided to the clients and the mean percent limitation decrease are listed in Table 3.

Table 3: Cost of services for RAGE's FY10 SCI clients

	Actual cost of services provided	Mean % limitation decrease
Total	$184, 077	100%
Mean	$ 8,367	67
Standard deviation	$ 7,860	20
Minimum	$ 717	30
Maximum	$ 31,550	100

Grouped by percent decrease in limitation. The mean percent limitation decrease for each of the clients was grouped into 10 percent intervals. The categories were mutually exclusive and exhaustive. The mean actual cost for services provided to each client in the group was tabulated. The frequency distribution of the grouped data is displayed in Figure 4.

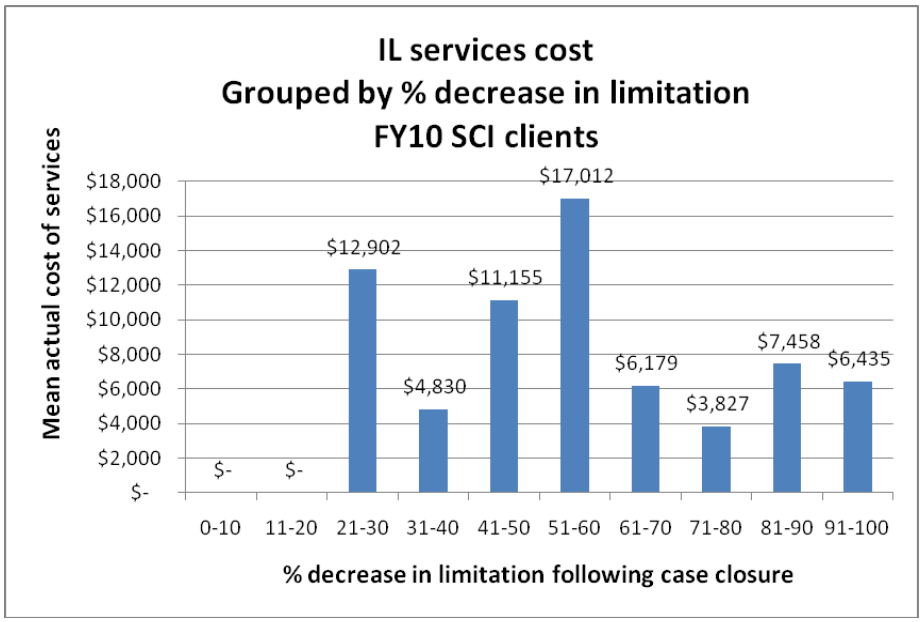

Figure 4: Mean services costs and percent decrease in limitation following case closure for FY10 SCI clients

The data indicates that the highest service costs resulted in a 50-60 percent decrease in functional limitation for the SCI clients. The small sample size and wide variation in services cost limits the comparison for this dataset. By including more data from other IL clients, the statistical analysis may provide a useful tool for RAGE to utilize to trend service costs and outcome level over time.

Grouped by years post disability onset. The difference from the date of disability onset and the age at the time of application to the RAGE program was used to calculate the years post disability onset for each client. The clients were grouped into age categories based on a model used by the NSCISC and the frequency of clients in each category was tabulated. The mean actual cost of services provided for each client within each group was calculated. The frequency distribution data is represented in Figure 5.

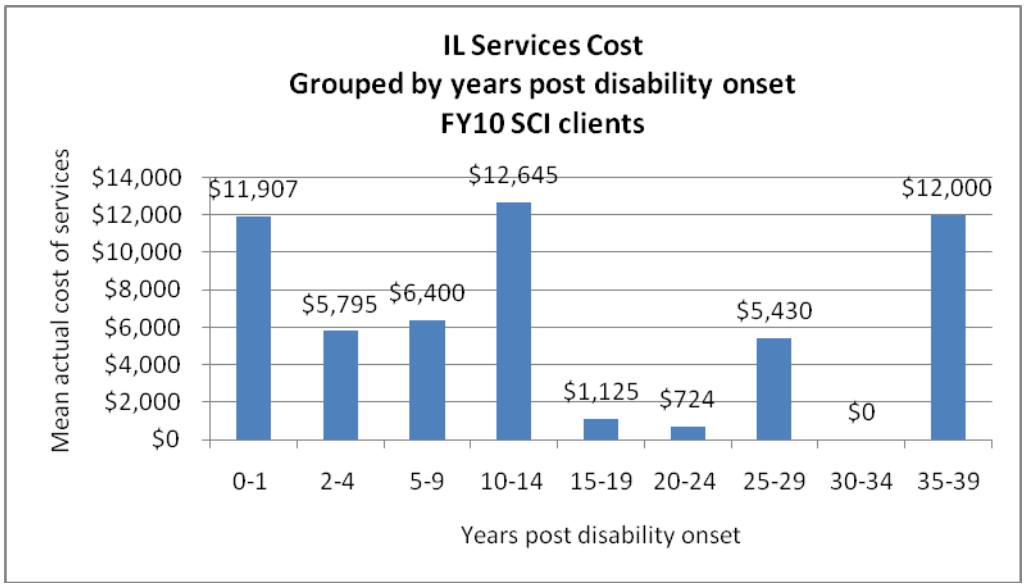

Figure 5: Mean service costs and years post onset of disability

According to the NSCISC statistics, the average yearly healthcare and living expenses for SCI clients is highest in the first year post disability, approximately $620,000 per year (all groups). Each subsequent year the average cost is approximately $95,000 per year (NSCISC,

n.d.). Home and vehicle modifications may not be included in these yearly estimates but are an important component of attaining self sufficiency for SCI clients. The data analysis shows a higher cost for services provided by RAGE to SCI clients in the first year post onset of disability. Additionally, the RAGE program provided 77 percent (17/22) of services to SCI clients within 0-14 years post onset of disability. This high level of service may reflect the success of the RAGE program at marketing their services to the SCI community and/or successful case management by the RAGE organization to identify appropriate services. There appears to be a trend showing an increase in average expenditure of approximately $12,000 every ten to fifteen years. This may be due to the aging of the client and/or caregiver which would require additional assistance to maintain the least restrictive living environment or could be indicative of the need for replacement equipment or improvements in assistive technology. Evaluation of this trending would require future study.

Conclusion

Based on analysis of the data provided by RAGE for the SCI clients, the agency's services have resulted in successful outcomes. The identified clients reported a decrease in their functional limitation, allowing them to maintain or attain the least restrictive environment. Additionally, the costs of services were higher for clients who were 0-14 years post onset, indicating that services were provided to clients with the most need (i.e., newly disabled or those requiring upgraded services). Finally, Appendix E provides examples of success stories of three SCI clients who received services from RAGE in FY10.

Limitations

Limitations to the study are noted below and could serve as a basis for further research. These include sample size, and both data and time constraints. First, the sample size was small

and short in duration; with restriction to just 22 SCI clients analyzed over a one-year period. It would be productive to consider a larger sample representative of the general population serviced by the agency over a longer period of time to more accurately capture and better evaluate the program's short-term or long-term outcomes.

Second, there were constraints regarding the data quality. Data quality is an important component of statistical analysis. Wang and Strong (1996) defined data quality as "data that are fit for use by data consumers" and developed a framework for data quality that includes the following areas:

- The data must be *accessible* to the data consumer. For example, the consumer knows how to retrieve the data.
- The consumer must be able to *interpret* the data. For example, the data are not represented in a foreign language.
- The data must be *relevant* to the consumer. For example, data are relevant and timely for use by the data consumer in the decision-making process.
- The consumer must find the data *accurate*. For example, the data are correct, objective and come from reputable sources. (Wang and Strong, 1996)

The data utilized in this study were based on a client's subjective rating of their limitation. Additionally, some of the information provided in the dataset was incomplete which may result in inaccuracies in calculations. Further, due to the small dataset, there was a wide variation in actual service costs which may inject bias in some of the calculations.

Finally, one significant limitation was the short time period allowed for the study. The project had to be completed within three months, preventing a more thorough analysis; and data availability was limited to a one-year period from the service agency. A longer time frame

would have allowed for more data collection, increased sample size, and possible comparison to a counterpart agency offering similar services.

Recommendations

It is evident that RAGE has made strides in assisting clients in improving their functionality at home, in mobility and in integration in the community as productive citizens. The positive client outcomes identified by the FY10 ADSD grant monitoring reports for the IL program were also seen in the data analysis performed on the subset of SCI clients.

Resolving the identified limitations in this initial study could provide a platform for assessing long-term outcomes in reference to the client's maintenance or attainment of the least restrictive environment and quality of life. Based on the data analysis, the following is recommended by the UNLV MPA students for the RAGE agency to pursue:

*Short-term recommendations***:**

- Improvement of data quality and accuracy.
- Performance of annual data analysis to identify trends and measure program outcomes.

Long-term recommendations:

- Utilization of a more refined assessment tool or standardization of their present limitation rating scale from 1-10 to 1-5.
- Examination of other factors that could impact program outcomes such as client's health and resilience, attendant care, services provided by other agencies, and needs for upgrade or replacement of equipment and modifications.
- Re-evaluation of subject SCI clients to ascertain if they retained functional independence at the same level or better since the initial closure in FY10.

- Performance of longitudinal study with an expanded client database.

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