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# Evaluating the Effectiveness of Adult Day Care on Alleviating Caregiver Stress/Burden

Lessep Duncan MA, MSW; Joan Bowla MSW; Rosena Tanis MSW

## ABSTRACT

*Though not extensive, the literature points to the efficacy of Adult Day Care (ADC) in alleviating stress on caregivers in several and differing ways. In line with this evidence, the findings from the evaluation of Northwest Focal Point's (NWFP) ADC program conducted by the Florida Atlantic University Evaluation Team indicates that ADC provides necessary relief and reduces the strain of caregiving on caregivers. Two measurement instruments: one to measure the level of caregiver strain and one to measure the effectiveness of ADC in alleviating this strain comprising five dimensions of caregiving strain and five dimensions of ADC impact in reducing strain were used to evaluate NWFP ADC program effectiveness. Whereas findings indicated that the ADC reduced caregiving strain in most dimensions, the evaluation pointed to the greatest impact of ADC was in increasing caregivers' confidence to provide care. Another significant impact identified in the evaluation related to the ADC reducing the caregivers' loved one dependence on the caregiver.*

*Florida Public Health Review, 2016; 13, 6-23*

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## BACKGROUND

One of the major goals of Adult Day Care (ADC) is caregiver respite. Yet, ADCs are closing and attendance is declining in face of increasing recognition of the impact of ADC on the lives of caregivers. Whereas ADC also impacts the loved ones of caregivers who actually attend ADC facilities, this evaluation focused on the efficacy of ADC in providing respite and easing the strain of caregivers.

The National Adult Day Services Association (NASDA), other Adult Day programs, and literature at times refer to Adult Day Care programs as Adult Day Services (ADS). Both ADS and ADC will be used interchangeably during this paper and indicate the same type of program. Unless stated otherwise, reference to Northwest Focal Point (NWFP) relates to the ADC program. Stress, strain and burden are also used interchangeably throughout this report.

## Executive Summary and Background

A Florida Atlantic University (FAU) Evaluation Team partnered with NWFP ADC for 10 weeks to evaluate the efficacy of the ADC program in alleviating the strain of caregivers. The FAU Evaluation Team constructed and implemented a Caregiver Assessment Instrument (Appendix A) to measure the level of caregiver strain and an ADC Assessment Instrument (Appendix B) to measure the impact of ADC on easing caregiver strain. The ADC program administered by NWFP Senior Center was approached because of its highly rated program. The

efficacy of the ADC program was assessed in line with five different dimensions: alleviating caregiver stress; enhancing caregiver ability (confidence) to provide care; providing a relevant (respite) resource; decreasing care recipient dependency on caregiver; and providing a positive impact on the caregiver's life.

Related goals included increased education and information for caregivers and producing information to:

- Make evidence-based decisions;
- Improve program quality;
- Provide relevant information and data for improved decision-making;
- Encourage outreach to potential clients;
- Increase funding sources; and
- Enhance advocacy

Aims and recommendations include:

- Increased knowledge of Caregivers situation;
- Increased collaboration/contact between Caregivers and ADC Staff/Administration; and
- ADC advocacy for and representation of caregivers

## Evaluation Purpose and Importance

Discussion with NWFP ADC Project Director, Program Manager and staff (including the Caregiver Support Group Coordinator), made it clear that services provide mutual and complementary benefits for both caregivers and ADC participants (as the

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*Florida Public Health Review, 13, 6-23.*

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NWFP Caregiver Support Group coordinator noted to be a goal of the ADC program). NWFP Staff agreed that alleviation of the stress of caregivers through ADC participation facilitated their loved ones adjustment to the program. Continued use of ADC services provided a significant indicator of the program's success. In constructing an appropriate measurement instrument to assess the impact on caregivers the NWFP Administration noted the possibilities of enhancing and expanding the program with information and results derived from the evaluation.

To elucidate the efficacy of NWFP ADC program the FAU Team conducted background research to assess the attention to and scope of the ADC service. This information also provided current views on the impact of Adult Day Care.

### Scope and Approach

The ADC program is one major service administered by NWFP Senior Center. Founded in 1976 to meet the increased demand for senior services in NW Broward County, the Center has been located adjacent to Margate City Hall since 1989. NWFP is administered by the City of Margate and operations are regulated by the Florida Department of Elder Affairs and the Area Agency on Aging of Broward County Inc. through the Older Americans Act of 1965. Matching funds are provided locally through donations and contributions. The NWFP ADC program provides social interaction and stimulation for adults offering varied age related activities in a supervised setting. The program runs Monday through Friday 8:00 a.m. until 4:00 p.m. with transportation available Monday through Friday from 7:00 a.m. – 3:00 p.m. ADC participants may be required to pay a minimal fee based on a sliding scale, may qualify for Medicaid funding or pay privately. The ADC program has approximately six permanent Staff members with several volunteers overseeing 20-30 clients during the course of the week.

Whereas literature is limited on the role and experiences of caregivers, evidence has pointed to the enormous financial and social benefits caregivers provide not only to their loved one but also on a societal level. The Preliminary Phase of the Evaluation lasting approximately five weeks comprised a series of meetings with ADC administration, program managers, and staff aimed at defining and committing to the subject and scope of the evaluation. It was felt by both the FAU Team and NWFP ADC administrator and program management that an evaluation could address this limited attention on caregivers and yield crucial information in assessing the effectiveness of and enhancement of the ADC program. Review of literature, including prior studies on caregiver strain

and ADC's impact in alleviating caregiver stress, was conducted by the FAU Evaluation Team.

The Final Phase of the Evaluation also lasting approximately five weeks and included distribution and collection of the measurement instrument including interviews with caregivers. Due to concerns with caregivers' privacy, NWFP administration assisted in disseminating the instruments with consent forms. The instrument was forwarded to all caregivers of program participants (as well as previous participants) totaling 40 caregivers. The results show the extent to which the NWFP ADC is successful in achieving its goal of alleviating caregiver strain and provide further information to enhance the program, increase funding, awareness and participation.

### Literature Review

Various electronic journals, databases, and Google Scholar were utilized employing Adult Day Care, Adult Day Services, Adult Day Care Evaluation and Caregivers as search terms. Advocating greater attention to and use of Adult Day Services (ADS) The National Adult Day Services Association (NADSA) working in partnership with MMI (MetLife Mature Market Institute) and The Ohio State University's Dr. Holly Dabelko-Schoeny and Dr. Keith Anderson, has identified 4601 day care programs operating in the United States. The 2009-2010 NADSA Census and Survey Project has shown this to be a 35% increase from 2002. Sadock and Sadock (2007) notes women-daughters and daughters-in-law 29%, wives 23% and other women 20%, are more predominant as caregivers than men due to societal and cultural expectations. They cite the American Association of Retired Persons (AARP) which points to daughters with jobs spending 12 hours on average providing care.

According to Gaugler and Zarit (2001) most caregivers (over 60%) were women, and 37% of caregivers were employed, (10%), of caregivers had either given up their jobs or reduced their work hours (30%), or taken time off without pay (20%) because of care responsibilities. Gaugler and Zarit's (2001) literature review included all studies of adult day care published after 1975 that focused solely on adult day care and evaluated adult day programs. They found the average age of participants to be 78, average enrollment 39.7 clients per program and time spent at the adult day care is usually two to three days a week for about five hours per day. Most participants are white, female, and unmarried, most clients are dependent on at least one activity of daily living and about half of adult day clients are cognitively impaired. Gaugler and Zarit (2001) study noted the numbers for the different models of Adult Day Care programs: 25%

medical models, 17% social models and the remainder comprised both medical and social. Whereas ADCs vary in terms of population, activities and services offered, according to Gaugler and Zarit (2001) overall evidence has not indicated significant physical improvement in functionality or removing the responsibility of care. Evaluations, however, have identified positive outcomes with regard to subjective and emotional experiences of clients and caregivers.

Jarrott and Zarit (1999) focused on Caregivers satisfaction with multiple specific aspects of services offered by Adult Day Programs for elderly relatives with dementia. Their study provided important indicators of the benefits and problems related to program utilization in ADS. Jarrott and Zarit (1999) assessed satisfaction, potential benefits and drawbacks of usage rather than with global indicators of overall satisfaction. Participants included 261 primary caregivers who were enrolling their relative with dementia in one of the 45 adult day service programs in New Jersey. The participants were interviewed in person to evaluate ADS programs immediately before their relative began attending the ADS program and again after three and 12 months of program use. A Likert Scale was used to assess satisfaction, ranging from one: low dissatisfaction to five: high satisfaction. There were areas in which some caregivers expressed dissatisfaction which included the times and number of days ADS was available (12% & 18%), transportation (21%) and cost of the program (13%). The study was useful in examining caregivers' subjective evaluation of ADS and their reports of programs benefits. While levels of satisfaction varied over time overall results revealed mean scores showing that caregivers were highly satisfied with aspects of the program their relative was attending including staff performance and program activities.

A study by Zarit, Stephens, Townsend, and Greene (1998) aimed at evaluating the effectiveness of ADC service and its impact on relieving caregivers stress and well-being. The study used a quasi-experimental design in which the treatment group used substantial amounts of services, whereas caregivers in a control group did not use day care at any point during the evaluation and only small amounts of respite services (Zarit et al., 1998). The study measured success of the program over a 5-month period and its positive impact on decreasing perceived stress, anxiety and somatic complaints but not depressive symptoms of caregivers. The study found that caregivers' life satisfaction increased over a 1-year period of day care. Over a 6-month period, caregivers in the treatment group reported an increase in morale and decrease in subjective burden (Zarit et al., 1998).

Caregivers interviewed, in a study by Warren, Kerr, Smith, Godkin, and Schalm (2003) indicated that the ADC program helped them better attend to the needs of the elderly person as well as contributed to better family relations. The study examined caregiver outcomes at 14 programs in Alberta, Canada, using a random sample of 10 pairs per site, with a total of 140 pairs (caregivers/elderly family member). After six months through the program, caregivers reported fewer hours involved in caregiving tasks relieving overload, worry and strain, depression and anger.

Addressing conflicting views regarding the impact of ADC on the reduction of Caregiver stress, a study by Zarit, Kim, Femia, Almeida, Salva, and Molenaar (2011) compared caregivers' exposure to and appraisal of behavior problems on days their relative attended and did not attend ADS. Participants were 121 family caregivers enrolling a relative with dementia in an ADS program. Daily assessments were obtained prior to the person's attending ADS for the first time and after 1 and 2 months of attendance on days the person attended and did not attend ADS. ADS use over a two-month period resulted in reduced stress exposure and stress appraisals as reported by family caregivers of people with dementia, and behavioral problems were lower in the evenings and nights following ADS use.

According to Gitlin, Reever, Dennis, Mathieu, and Hauck (2006) Adult Day Services Plus (ADS Plus) is a cost-effective care management intervention tailored to improve the family caregiver's well-being, increase service utilization and decrease nursing home placement. They examined the short and long-term benefits to caregivers. Gitlin et al. (2006) found that the intervention systematically helps family caregivers develop problem-solving and coping skills, improve social and instrumental support, and enhance perceived competence in managing the difficult behaviors of their impaired elder.

The study used a quasi-experimental design to recruit 129 caregivers from three adult day centers and incorporated the help of a staff social worker who provided care management and support to the family caregivers through face-to-face telephone contacts, psycho-education, counseling and referral services over a 12-month period. After 3 months, ADS Plus participants reported less depression, improved confidence managing behaviors and enhanced well-being. At the end of the 12-month period, the evaluation of the ADS Plus Program resulted in long-term clinically significant quality-of-life improvements for the caregiver and the impaired older adult resulting in fewer nursing home placements (Gitlin et al., 2006).

The literature points to clear benefits of Adult Day Care Services where caregivers are happy because

their relatives liked and were well cared for in the ADS program. Evidence has indicated caregiver stress relief from use of ADC's. Types of stress focused on include overload, strain and role captivity (Zarit, 2001). Noted benefits include social and health maintenance, rehabilitation, and caregiver respite (Lucas, Rosato, Lee, & Howell-White, 2002). The University of Wisconsin Milwaukee (UWM) Center on Age & Community Fall 2010 Forum identified a requirement to increase awareness of family needs by conducting research and assessments to identify: (1) the needs of family members in ADS; (2) the benefits families are currently receiving; and (3) the benefits families hope to receive in the future. Focusing on Adult Day Services as an Essential Source of Support for Family Caregivers, the Forum points to:

- Adult day services provide a reliable source of support, restore balance in times of crisis, and enhance overall quality of life for caregivers;
- Adult day services provide respite to family caregivers;
- Over 80% of participants attend full days and 46% attend five days per week, enabling family caregivers to remain in the workforce; and
- Most centers provide caregiver support programs, including educational programs (70%), caregiver support groups (58%), and individual counseling (40%).

Schacke and Zank (2006) note numerous studies have reported the immense difficulties caregivers face in caring for a care recipient/family member, loved one etc. Their study focuses on an evaluation of ADC considering several dimensions of caregiver stress based on qualitative data using semi-structured interviews analyzed by content analytical techniques. Schacke and Zank (2006) also used response scales to measure levels of stress and to produce a statistical analysis. Their results indicated that use of ADC reduced stress levels in several different dimensions: job requirements, family needs and recreational pursuits. Researchers note limitations in measures used which indicated ADC may reduce specific types of stress, though other types and aspects of stress may be identified using different measurement instruments.

Evidence and experience reveal that day care centers provide increasingly essential services for clients, caregivers, and families. Studies including research by Gaugler and Zarit (2001) have pointed to the benefits gained by caregivers in the extent of ADC use. Authors argue that consistent use of ADC as a

component of multiple support services provides significant relief and alleviates caregiver strain.

## METHODS

### Orientation and Hypothesis

Whereas the NWFP ADC program serves to provide social interaction as well as stimulation, supervision and assistance with Instrumental Activities of Daily Living for the attendees (caregivers loved ones) this evaluation focused on the impact of ADC on the caregiver. The research question employed was: *How effective is NWFP ADC program in reducing the strain/burden of caring for care recipients on caregivers provided clarity and a common focus for all stakeholders?* Our hypothesis was: *Adult day care eases caregiver burden.*

In collaboration with NWFP Administration, we decided that the ADC assessment instrument could indicate how far caregiver strain is alleviated by use of ADC. Schacke and Zank (2006) argue that studies on the effectiveness of ADCs are deficient in 3 criteria: (1) theoretical conceptualization and measurement of caregiving strain; (2) the appropriateness of outcome criteria; and (3) the appropriateness of the study design. Schacke and Zank (2006) point to a requirement for relevant conceptualization that measures specific dimensions of caregiving stress or strain that focuses on the caregiver's situation rather than broader definitions that ignore or distort the cause and nature of strain suffered.

In terms of the present study *caregiver* was defined as a relative, friend, or partner with a significant close relationship with an ADC participant who provides assistance with Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL). ADC is defined as a source of social interaction and stimulation for adult participants in a licensed facility with qualified staff providing respite to caregivers. *Strain* is defined as a subjective perception of the effects of caregiving on caregivers' emotional and psychological well-being and as objectively measured from the role of caregiving that effect caregivers daily functioning including reduced time spent on desired/leisure activities.

### Research Design

A triangulation method approach was employed. This comprised results from two semi-structured measurement instruments (adapted from a Zarit Burden instrument) to meet the characteristics of caregivers of NWFP ADC participants, review of the program goals with NWFP staff, and existing literature to increase the validity and substance of information produced by the measurement instruments. The two

adapted measurement instruments constructed addressed NWFP caregiver circumstances and included terminology to increase the response rate and prevent any further stress of caregivers.

The NWFP ADC administrators, program management and staff viewed this as an opportunity to gain direct insight from an intended user population i.e., caregivers; further data indicating the extent to which their program eased caregiver strain; and information to facilitate an improvement of program delivery and outcome.

Noting the importance of both qualitative and quantitative data, the two semi-structured measurement instruments used in this evaluation project were: A Caregiver Assessment Scale (focusing on the level of strain felt providing care) [Appendix A] and an Adult Day Assessment Scale (focusing on the extent to which ADC alleviated strain) [Appendix B]. The measurement tools were selected and adjusted to meet the characteristics and circumstances of NWFP ADC caregiver population. Both included a Likert scale along with a section for elaboration of the caregiving experience and impact of ADC in terms of five different dimensions.

A Zarit Caregiver Burden Scale with a Likert Scale ranging from 0-4 was adapted as per above concerns. Zarit's Burden Scale is used frequently and interchangeably. Introduced in 1980 the Zarit Burden Scale has been revised on several occasions and used to assess various aspects of caregiving burden/strain (Zarit, Reever, & Bach-Peterson, 1980). The instrument can be used in both clinical and community settings as a self-report questionnaire. It enables subjective perception of burden of caregivers. It has good construct validity and reliability with excellent internal consistency; Cronbach's alpha = 0.83 and 0.89 and a test-retest reliability of 0.71.

The adapted Zarit Burden Scale comprised five separate dimensions with several questions in each dimension. The FAU Evaluation Team was aware that the five dimensions do not fully capture the extent of caregiver strain. However, using the five dimensions the evaluation was able to identify specific quantitative categories as well as common qualitative themes and trends in assessing levels of strain and how well NWFP ADC was successful in alleviating this strain. (An ADC Assessment Scale included a similar Likert Scale also comprising five dimensions with questions in each dimension was also adapted to address corresponding [reduction] of stress/strain from the Caregiver Burden Scale).

Objective measures of ADC effectiveness were obtained from scores indicated in dimensions of burden and alleviation levels. Subjective information

was derived from caregivers input on reduction of strain/stress in sections for elaboration on the assessment instruments.

In response to NWFP ADC administration concerns regarding caregiver confidentiality and participant protection during the evaluation, the instruments were distributed, with consent forms and an option to complete and return the two measurement instruments anonymously or agree to be interviewed, to current and previous caregivers of past ADC participants (last five years) by ADC Staff and administration. This totaled 40 caregivers.

Caregivers (respondents) agreeing to be interviewed contacted an FAU Evaluation Team member and an appointment was arranged for the interview to be conducted at the caregiver's home or in a private room at NWFP. Caregivers were asked questions by an FAU Team member using the adapted Caregiver Assessment of Burden and the ADC Caregiver instruments. The interviewer used the section at the end of each question to enable the caregiver to elaborate on their caregiver experiences. This information was used to elicit themes and prevailing indicators of the impact of ADC on caregivers' lives.

The Dimensions for the Caregiver Assessment (Appendix C) included:

- Enough time to maintain control and address responsibilities;
- Uncertainty caring for loved one;
- Feelings of strain;
- Negative impact on life; and
- Fear that your care is not good enough.

The Dimensions for ADC Assessment (Appendix D) included:

- How much relief does ADC provide for self and from responsibilities?
- How far does ADC reduce feelings of Uncertainty?
- How much strain does ADC reduce?
- Positive impact on life? And
- How far does ADC reduce your fear that your care is not good enough?

### Research Activities

Due to NWFP staff, administration and management concerns for the use of the word "burden" in relation to caregiver stress and caregiver privacy, both instruments were adjusted to elicit a greater response rate. Aimed at increasing the population to be interviewed a joint decision – between FAU Team and NWFP administration and program management – was

agreed to include caregivers of previous ADC participants.

Discussion also included the manner in which this instrument was to be provided and consent of caregiver obtained to participate in the project. This led to a series of further meetings and discussion as to how best to protect caregivers' privacy. Careful attention was paid to the design of the consent Form (Appendix E) to participate in the evaluation project which was subsequently constructed via productive collaboration between FAU Team and NWFP administration and management.

### **Survey Development and Administration**

NWFP ADC had no current instruments measuring the impact of ADC on Caregivers' lives or stress levels. This led to several meetings to construct a suitable instrument, as well as an appropriate consent form for participants in the evaluation. Several issues were reviewed including a concern with the participant's privacy, likely response rate and revision of measurement instruments to avoid exacerbating possible stress levels. This led to a requirement for NWFP ADC administration to initiate contact with caregivers and to distribute the measurement instruments.

The collaborative effort between the FAU Team and NWFP ADC Director and program manager also fostered recognition of common concerns and potential for further research.

### **Data Collection**

Returned measurement instruments including Likert scale scores and additional subjective elaboration were collated and reviewed. Discussion with the NWFP ADC staff along with the literature review was also used as additional information on which the evaluation based. Collected data was for the purposes of the evaluation study only. Likert scale responses provided quantitative measurements which included: no; minimal; moderate; high; or very high measures of caregiver strain on the Caregiver Assessment Instrument and no alleviation; minimal alleviation; moderate alleviation; high alleviation; and very high alleviation of strain on the ADC Assessment Instrument. These responses were recorded on each instrument and an average score for each question obtained by dividing the total responses for each question by the number of participants. An overall average for level of strain and extent of alleviation were calculated by adding the averages for each response and recorded at the bottom of both caregiver and ADC instruments (Appendix A and B). Giving the caregivers (respondents) the choice of remaining

anonymous or participating in an interview with a member of the FAU Evaluation Team while providing a section on the instruments for subjective input, both quantitative and qualitative information was gained.

### **Data Analysis Techniques**

Analysis of the collected data included calculating an average score for each question on both caregiver and ADC instruments (Appendix A and B). This entailed multiplying the amount of responses to each category by the category responded to (e.g., if two respondents selected the score of 2 on the Likert scale [0-4] in answer to a particular question a calculation of 2x2 would be made and added to any further selections from the Likert scale for the same question. This would be divided by the total amount of responses for that question, indicated in parenthesis, to produce the average/mean score). The averages/means for each question were added to produce an overall score. The interpretation (derived from Zarit's Burden Scale) was used to determine the level of strain from the Caregiver instrument (Appendix A) – and alleviation of strain from the ADC instrument (Appendix B).

The statistical data was augmented by qualitative responses derived from sections on the instruments for subjective elaboration and during meetings with caregivers who agreed to be interviewed. Due to a reduction in NWFP ADC enrollment and lack of attendance only 26 of the 40 Measurement Instrument and Consent Form packages were distributed to caregivers. Of these 26, 11 caregivers responded, completing the instrument anonymously or via the instrument and interview. This amounted to a response rate of just over 40%. Whereas this is a reasonable response rate, the small sample limited generalization of evaluation findings.

## **RESULTS**

The caregiver instrument (Appendix A) attempted to ascertain the level of burden the caregivers experienced when caring for their relatives and indicated an overall score of 34.5: Mild to Moderate Burden on the rating scale. Although caregiver responses to questions indicated no significant loss of control over their lives, or their health, privacy and relationships with friends and family, their responses indicated a moderate burden felt for caring for their loved one and a strong sense of responsibility to provide care. Caregivers also reported a moderate sense of strain, poor social life, and a fear of not being to care for their loved one.

The scores on the ADC instrument totaling – 40.3 indicated a moderate to high reduction of caregiving strain by the ADC. A review of ADC instrument

survey samples collected indicated that on an average the ADC provided caregivers enough time for self, reduced feelings of being overtaxed and restored control over their lives. A moderate to high level was reported for the confidence ADC gave caregivers in feeling that they are facilitating an appropriate service for their relative, doing a good job caring for their relative, as well as reducing a sense of strain. Responses to questions concerned how the ADC reduced the feelings of uncertainty about what to do for relatives; reduced the anger felt by caregivers; reduced feelings of fear about the future of a relative; reduced the fear of not being able to continue caring for the relative; reduced the desire to surrender the care of relative to someone else and how it improved the caregivers' health, privacy, and relationships with family and friends indicated minimal success.

Condensing the questions on both instruments to five dimensions on each, both statistical and qualitative data were examined for common themes among the caregivers' responses. Average scores for dimensions on both instruments are indicated below.

The Dimensions for the Caregiver Assessment (Appendix C) with averaged scores include:

*Dimension 1* – Enough Time to maintain control and address responsibilities (-1.9)

*Dimension 2* - Uncertainty caring for loved one (-1.5)

*Dimension 3* – Feelings of strain (-2)

*Dimension 4* – Negative impact on life (1.9)

*Dimension 5* – Fear that your care is not good enough (2.6)

The Dimensions of the Adult Day Care Instrument with average scores (Appendix D) include:

*Dimension 1* – How much relief does ADC provide for self and from responsibilities? (-2.7)

*Dimension 2* –How far does ADC reduce feelings of uncertainty? (-3)

*Dimension 3* –How much strain does ADC reduce? (-2.7)

*Dimension 4* –Positive impact on life (-2.3)

*Dimension 5* –How far does ADC reduce your fear that your care is not good enough? (-1.7)

Qualitative analysis of caregiver interviews regarding caregiving strain indicated:

*Dimension 1* – A major theme: A sense of responsibility as a caregiver. While time for self was limited throughout, responses ranging from being overwhelmed to feeling good about the caring role, indicated a sense of responsibility of caregiver to provide care.

*Dimension 2* - A desire to do what is best for the loved one – a 'natural' or expected feeling. Feelings of uncertainty were reduced by a striving to do what

is best for the loved one. Responses ranged from doing the best with limited resources to an expectation to be responsible for the care of the loved one.

*Dimension 3* – Limited or no anger towards the loved one. Caregiver does feel the strain of caregiving. Caregivers indicated awareness that anger does not ease their strain or loved one's condition of dependence and requirement for care.

*Dimension 4* – Support from family, friends viewed as welcome where available. While social supports mitigated a negative impact of caregiving the caregivers generally retained a sense of responsibility as the caregiver and main source of care and assistance.

*Dimension 5* – A major theme related to the loved one's dependence on the caregiver. Caregivers generally embraced this responsibility. Responses ranged from being able and expected to provide necessary care to defining their daily life and identity as a caregiver.

Themes identified from qualitative information on ADC efficacy:

*Dimension 1* – ADC generally increased personal time for caregivers.

*Dimension 2* – A major theme: Use of ADC produced a view that the right service with qualified, caring staff employed to assist with care of loved one was chosen. This increased the caregivers' confidence in themselves and their ability to maintain care of their loved one.

*Dimension 3* - Overall ADC reduced a feeling of strain – though anger not a major factor.

*Dimension 4* – Varied responses – included increase in time for social activities, reducing worry about the loved one, though the caregiving role remains central to the caregiver's life. ADC cannot replace the caregiver.

*Dimension 5* – Overall ADC reduces dependency on the caregiver. However the caregiver retains a sense of responsibility.

## Findings

Quantitative data from survey instruments and qualitative information from interviews and caregiver elaboration indicates that caregiving does cause strain though levels were lower than expected. Data also indicates ADC reduces strain. ADC increases the caregiver's confidence and enhances the caregiver's ability to provide care; reduces care recipient dependency and provides respite to ease caregiving strain. While not taking the responsibility away from caregiver ADC has increased caregivers knowledge of,

a requirement for as well as availability of assistance and assurance that requesting assistance is OK.

A major theme identified from qualitative information: ADC Increases confidence of caregivers who feel that the right service is provided by the right people. Though the caregiver retains responsibility of care ADC provides the caregiver with respite in the knowledge that their loved is appropriately supervised and cared for by responsible and qualified staff. Comments included ADC is the best thing since sliced bread; ADC does a good job. Responses indicated ADC services as therapeutic, stimulating; produces a good feeling (for the caregiver).

## DISCUSSION

### Meaning and Relevance

Caregivers live in an increasingly complex world where navigating through a varied and multiplicity of programs ascertaining applicable assistance is becoming a greater concern. This requires increased attention to caregivers concerns and fuller examination of relevant links between purpose of program and need of the caregiver as well as the other stakeholders. ADC addresses several needs and meets several goals. These include psychological and emotional benefits to caregivers (Gaugler and Zarit, 2001; Zarit et al, 1998; Warren, Kerr, Smith, Godkin, & Schalm, 2003; Zarit et al 2011; Zarit 2001); satisfaction with services offered and staff (Jarrott and Zarit, 1999); prevention of Nursing Home placement (Gitlin et al, 2006); social and health maintenance, rehabilitation, and caregiver respite (Lucas, Rosato, Lee, Howell-White, 2002); and impacting occupational and social life (Schacke and Zank, 2006).

Indeed the UWM 2010 Forum viewed ADC as an essential source of support for family caregivers. NADSA advocates expansion of ADC as a viable community-based care option among other supportive services for an increasing diverse people including those with disabilities and the elderly. NADSA argues for ADCs' to be assessed in terms of six quality domains: safe, effective, person-centered, timely, efficient, and equitable service. Concerns expressed by NWFP regarding both attendees and caregivers including confidentiality and disruption in program participation indicated the programs attention to these domains. Recognizing these concerns the evaluation was conducted in line with NASW Code of Ethics. The evaluation included themes related to the Code of Ethics core values and recognized how the ADC meets these values:

- Service – ADC is people oriented and aims at addressing caregiver stress and providing attendees with stimulation and interaction

- Social justice – ADC provides fair and equal access to people of all cultures
- Dignity and worth of the person – ADC provides respectful service that recognizes the client's needs and empowers caregivers
- Importance of human relationships – ADC services in an interactive social setting
- Integrity – ADC provides service from sensitive staff in a licensed facility
- Competence – ADC provides services from qualified staff who receive ongoing training

Whereas NWFP lacked evaluation information and instruments regarding caregivers the ADC program operated in line with the above core values. Indeed NWFP administration concerns regarding caregiver confidentiality enabled discussion with the FAU Team to address many Code of Ethics standards. In the main standards related to Service to Clients: S.1.03 Informed Consent (a) and (b); this is indicated their S.1.01 Commitment to Clients (i.e. desire to protect rights to privacy); giving the participants an option to refuse to participate addressed caregivers 1.02 Self-determination; S.1.05 Cultural Competence and Social Diversity (a), (b) and (c) was included in discussions; all sections of S.1.07 Privacy and Confidentiality were addressed and used in constructing the Informed Consent; NWFP staff made sure participants services were not disturbed recognizing: S1.15 Interruption of Services. All aspects of S5.02 Evaluation and Research were addressed along with S6.01 Social Welfare.

### Filling a Gap

In the absence of any current evaluations this evaluation will provide NWFP with pertinent information to elucidate the ADC program's impact on caregivers and contribute to subsequent evaluations. Although this evaluation focused on single ADC program the NWFP administration and management viewed this as similar to other ADC programs and felt this enabled a degree of generalization of findings. Day Care Centers enable Families of diverse types (nuclear, extended, single parent, etc.) including differing cultures to continue 'normal' active life in the knowledge that the service recipient is being cared for by qualified Staff.

According to Warren, Kerr, Smith, Godkin, and Schalm, (2003) research has indicated that although ADC Programs for elderly people have been implemented throughout North America, they are not widely evaluated for their impact on family caregivers. This view is reinforced by a report from the Family Caregivers Alliance (2006) arguing that emphasis should be placed on how service providers can help the

family not just how the family can help the relative. Pointing to differing (though limited) sources of support for Caregivers and even fewer studies and evaluations on the effectiveness of ADC Programs it is essential to identify their efficacy and availability (Schacke & Zank, 2006).

In a slightly different vein, Zarit (1989) pointed to an overly exclusive focus of studies on caregiving stress. He argues that to fully address this concern requires community interventions comprising collaborative efforts between researchers, providers and funding agencies. Zarit (1989) makes a crucial point noting collective projects that include and encompass all relevant users and beneficiaries for accurate perceptions of a program's impact. This enables a fuller picture of a program's efficacy rather than further studies on caregiver stress. Subsequent discussion with NWFP staff enabled NWFP staff to elaborate on increased and new emphasis on the caregivers' role. Indeed NWFP administration notified the FAU Evaluation Team of new caregiver initiatives including educational workshops and new funding to assist not only with loved one's attendance at ADC but further avenues of respite and caregiver support.

Thus, the initial stakeholder and subsequent collaborations with NWFP administration and staff proved vital in obtaining participant responses and feedback, necessary to conduct the evaluation. Acknowledging differing experiences of caregivers including coping strategies and positive aspects of caregiving includes fostering productive relationships between ADC staff and caregivers. Zarit (2001) points to the ways services are implemented, received and utilized as enabling the caregiver to cope and, in line with findings of the present study, to increase confidence in the role as caregiver.

Positive interaction between NWFP ADC and caregivers was found to increase caregivers trust in ADC as a beneficial service. Caregivers felt less stress and demands as the relative was not with them all the time. Caregivers also felt a sense of freedom from caregiving responsibilities and increased time to do what they enjoyed while the relative was at the ADC. A sense of relief and increase in confidence in their ability as caregivers was a major finding. This is related to the loved ones enjoyment of social activities and receipt of expert care at the ADC.

### **Implications for Public Health**

Discussion among the FAU Team and NWFP regarding the ADC program served to highlight the ways ADC addressed many of the values and standards underpinning the social work profession and code of ethics. Addressing its responsibilities to use

government funding along with other resources to provide relevant services: supervision, interaction for attendees and respite for caregivers by qualified staff, NWFP has achieved a regular (though at times low) attendance. Short-term outcomes include Caregiver relief, medium outcomes achieved were trust and confidence in ADC by caregivers and long-term outcomes include support to caregivers to retain attendees in the community.

Although this evaluation focused on the efficacy of ADC to ease the caregiver burden evidence also indicated that NWFP service closely meets the six domains advocated by NADSA. The evaluation elicited a general view of the impact of ADC using a Likert Scale. Outcomes identified as successful included: For the caregiver:

- It appears that the ADC makes the caregivers feel confident about providing care and that the caregiver is doing a good job providing care.
- Information from the evaluation indicated that ADC improves the caregiver outlook, emotional and psychological well-being.
- This in turn facilitates or maintains a positive relationship with their loved ones, an ability and motivation to provide physical and emotional care.
- This leads to greater confidence in their role of caregiver and willingness to retain responsibility of their loved one.

The ADC program provides:

- A sensitive and supportive staff;
- Attention given to caregivers – though attendees viewed as primary focus;
- A service beneficial at the personal, family and community level;
- The evaluation pointed to the usefulness of ADC in improving caregivers' sense of efficacy and reducing the strain of caregiving; and
- Evidence has pointed to its efficacy at varied levels making it an increasingly useful service and perhaps a requirement in every city or locale.

For the community or society-at-large, use of ADC can be shown to be an economic benefit to employers such as increased productivity of working caregivers, fewer days of work missed preventing loss of income for caregivers, reduction in health related costs. Thus,

at a several levels ADC can be considered to be cost-effective:

- Financial: reduces government spending on nursing homes and assisted living facilities;
- Social: as a community resource, ADC provides a source of support and assistance; and
- Personal: services maintain attendees in their homes and support caregivers to provide care.

### Limitations

Using only one ADC program with only just over 40% response was a limitation. This may indicate a lack or limited interest in either the evaluation or program. However, evidence from the measurement instruments and interviews point to the caregiver priority providing care limiting time to participate in the evaluation. Whereas it remains crucial to protect the privacy and confidentiality of caregivers, the information gained, and the comments and requests made during interviewing indicated caregivers have a desire to explain their situation in more detail than a semi-structured instrument would allow. The meetings and discussion with NWFP Administration regarding caregivers' privacy pointed to the NWFP recognition and concern for caregivers' rights and dignity. This indicated NWFP willingness to take the necessary time to protect the caregivers' privacy – a vital issue. However, this reduced direct contact with the FAU Evaluation Team. Although responses to the Likert measurements provided important, indeed significant information to assess the efficacy of NWFP's ADC program it lacked deeper insights of the impact of ADC in easing caregiving strain derived from the caregivers' experience.

### Recommendations

There is a requirement for increased education of and information to be provided to the caregiver regarding the benefits of ADC. Increased promotion of ADC through NWFP Staff notifying caregivers of available state and community based programs to subsidize cost of ADC for caregivers as well as public awareness drives and outreach initiatives should be considered.

- Review of ADC application packages to include recognition of caregivers' situation would increase and enhance relationships between caregivers and NWFP ADC program as well as provide necessary information to facilitate advocacy for further ADC funding.

- Education and dissemination of relevant information can lead to access to further resources and services i.e., Caregiver support groups, other forms of respite used along with ADC to increase the efficacy of ADC.
- Increased public awareness of available and applicable agencies and services is required for public involvement in discussion of community needs.
- Input from caregivers and further knowledge of caregivers' experiences should be applied to support current ADC services and redefine programs. Caregiver perspectives and needs should be ascertained in the design, implementation and delivery of services.

As evidenced during interviews qualitative methodologies appeared to produce insightful and meaningful information. Perhaps with further education and communication between NWFP staff and caregivers including awareness of evaluation intent caregivers will become more willing to participate in direct interviewing.

### Summary: ADC Increases Caregiver Confidence

This evaluation is supportive of the view expressed by Gaugler and Zarit (2001) that the optimal use of ADC occurs when it is employed in conjunction with other interventions. The data and evidence points to the efficacy of ADC alleviating stress on the caregiver by enhancing the existing care and assistance the caregiver provides. While the ADC does not remove the dependency on or responsibility of the caregiver ADC does provide a relevant, helpful and appropriate source of care that makes the caregiver's feel they doing the 'right thing'.

Elaboration and particularly interviews provided deeper insight and exploration of caregivers' lives and caregiving activities. Information gained during these interviews pointed to direct interviewing as an advantageous means of exploration and examination of caregivers lives and experiences. Caregivers believe that their relatives receive care and attention from qualified and caring staff, are involved with other ADC participants (peers) in social activities and interaction that are of therapeutic value. Caregivers are able to develop a productive relationship with the ADC staff which increases their sense of assurance, enhancing their role as caregivers knowing that their relatives' well-being is provided for in a stable, social and stimulating environment. The caregivers can receive feedback and information on any physical and emotional concerns from staff about their relatives (care recipients) through regular monitoring and

supervision. This supplements and reinforces the ongoing care from the caregiver. Further support through caregiver support groups, outreach and education provided in addition to ADC can provide necessary benefits to caregivers and significantly reduce their strain. Thus in conjunction with confidence in the ADC, ADC enables caregiver to meet their responsibilities and have increased confidence in their role to continue to provide care.

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**Appendix A: Caregiver Assessment Scale - Averaged Scores**

<b>Caregiver Assessment Scale</b>
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Read each statement and rate it on a scale from 0 (never), 1 (occasionally), 2 (sometimes), 3 (often), 4 (always)

**In general, how often do (did) you feel:**

There is not enough time for yourself	0	1	2	3	4	Av. score
<b>Scores for each measure</b>	<b>2</b>	<b>5</b>	<b>4</b>	<b>(11)= 2.2</b>		

Overtaxed with responsibilities	0	1	2	3	4	Av. score
<b>Scores for each measure</b>	<b>2</b>	<b>5</b>	<b>2</b>	<b>1</b>	<b>(11) = 2</b>	

Like you've lost control over your life	0	1	2	3	4	Av. score
<b>Scores for each measure</b>	<b>4</b>	<b>4</b>	<b>3</b>	<b>(11)= 1.5</b>		

**In regard to the relative for whom you are (were) caring, how often do (did) you feel:**

Uncertain about what to do for your relative	0	1	2	3	4	Av. score
<b>Scores for each measure</b>	<b>5</b>	<b>2</b>	<b>2</b>	<b>1</b>	<b>1</b>	<b>(11)= 1.2</b>

Like you should do more for your relative	0	1	2	3	4	Av. score
<b>Scores for each measure</b>	<b>3</b>	<b>1</b>	<b>4</b>	<b>2</b>	<b>1</b>	<b>(11)= 1.7</b>

Like you could do a better job of caring	0	1	2	3	4	Av. score
<b>Scores for each measure</b>	<b>3</b>	<b>2</b>	<b>4</b>	<b>1</b>	<b>1</b>	<b>(11)= 1.5</b>

**When you are (were) with the relative for whom you are caring, how often do (did) you feel:**

A sense of strain	0	1	2	3	4	Av. score
<b>Scores for each measure</b>	<b>3</b>	<b>3</b>	<b>3</b>	<b>2</b>	<b>(11)= 2.4</b>	

Anger	0	1	2	3	4	Av. score
<b>Scores for each measure</b>	<b>1</b>	<b>6</b>	<b>2</b>	<b>1</b>	<b>1</b>	<b>(11)= 1.5</b>

**How often do (did) you feel that your relationship with the relative for whom**

**You are (were) caring negatively impacts:**

Your social life	0	1	2	3	4	Av. score
<b>Scores for each measure</b>	<b>1</b>	<b>2</b>	<b>2</b>	<b>5</b>	<b>1</b>	<b>(11) = 2.3</b>

Other relationships with family and friends	0	1	2	3	4	Av. score
<b>Scores for each measure</b>	<b>2</b>	<b>2</b>	<b>4</b>	<b>3</b>	<b>(11)= 1.7</b>	

Your health	0	1	2	3	4	Av. score
<b>Scores for each measure</b>	<b>2</b>	<b>1</b>	<b>3</b>	<b>4</b>	<b>1</b>	<b>(11) = 2</b>

Your privacy	0	1	2	3	4	Av. score
<b>Scores for each measure</b>	<b>4</b>	<b>2</b>	<b>1</b>	<b>2</b>	<b>2</b>	<b>(11)= 1.6</b>

**How often do (did) you:**

Feel all the responsibility falls on one caregiver	0	1	2	3	4	Av. score
<b>Scores for each measure</b>	<b>1</b>	<b>3</b>	<b>2</b>	<b>5</b>	<b>(11)= 3</b>	

Fear the future regarding your relative	0	1	2	3	4	Av. score
<b>Scores for each measure</b>	<b>3</b>	<b>1</b>	<b>1</b>	<b>4</b>	<b>2</b>	<b>(11)= 2</b>

<u>Fear not being able to continue caring for your relative</u>	0	1	2	3	4	Av. score
<b><u>Scores for each measure</u></b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>2</b>	<b>3</b>	<b>(11)= 2.5</b>
<u>Wish to leave the care of your relative to someone else</u>	0	1	2	3	4	Av. score
<b><u>Scores for each measure</u></b>	<b>5</b>	<b>2</b>	<b>2</b>	<b>2</b>	<b>(11)= 1.5</b>	
<u>How much does your spouse/loved one depend on you as the caregiver?</u>	0	1	2	3	4	Av. score
<b><u>Scores for each measure</u></b>	<b>1</b>	<b>10</b>	<b>(11)= 3.9</b>			

**Total Score 34.5 indicating Mild to Moderate Burden**

**Please rate your overall level of burden in caring for your spouse/relative/care recipient:**

(0) No burden at all (1) Mild Burden (2) Moderate Burden (3) Severe Burden (4) Extreme Burden

**Interpretation:**

- a. No or minimal burden: 0 to 20
- b. Mild to moderate burden: 21 to 40
- c. Moderate to severe burden: 41-60
- d. Severe burden: 61 to 88

**Appendix B: Adult Day Care Assessment Scale - Averaged Scores**

*We are asking these questions to assess the Adult Day Care's impact on your life*

Read each statement and rate it on a scale from 0 (never), 1 (occasionally), 2 (sometimes), 3 (often), 4 (always)

**In general, how often does (did) ADC:**

Provide enough time for yourself	0	1	2	3	4	Av. score
<b>Scores for each measure</b>	-	1	2	6	2	(11)= 2.8

Reduce feelings of being Overtaxed with responsibilities	0	1	2	3	4	Av. score
<b>Scores for each measure</b>	-	1	2	6	2	(11)= 2.8

Restore control over your life	0	1	2	3	4	Av. score
<b>Scores for each measure</b>	1	1	2	6	1	(11)= 2.5

**In regard to the relative for whom you are (were) caring, how often does (did) ADC:**

Reduce feelings of Uncertainty about what to do for your relative	0	1	2	3	4	Av. Score
<b>Scores for each measure</b>	3	-	2	6	-	(11)= 2

Make you feel confident you are facilitating an appropriate service for your relative	0	1	2	3	4	Av. Score
<b>Scores for each measure</b>	-	-	-	5	6	(11)= 3.5

Make you feel you are doing a good job of caring	0	1	2	3	4	Av. Score
<b>Scores for each measure</b>	1	-	-	3	7	(11)= 3.4

**When you are with the relative for whom you are (were) caring, how often does (did) ADC:**

Reduce A sense of strain	0	1	2	3	4	Av. score
<b>Scores for each measure</b>	-	-	2	6	3	(11)= 3

Reduce Anger	0	1	2	3	4	Av. score
<b>Scores for each measure</b>	1	2	3	3	2	(11)= 2.3

**How often does (did) ADC make you feel that your relationship with the relative for whom**

**You are (were) caring positively impacts:**

Your social life	0	1	2	3	4	Av. score
<b>Scores for each measure</b>	1	1	3	4	2	(11)= 2.5

Other relationships with family and friends	0	1	2	3	4	Av. score
<b>Scores for each measure</b>	1	1	6	3	-	(11)= 2

Your health	0	1	2	3	4	Av.score
<b>Scores for each measure</b>	<b>1</b>	<b>1</b>	<b>4</b>	<b>4</b>	<b>1</b>	<b>(11)= 2.3</b>
Your privacy	0	1	2	3	4	Av.score
<b>Scores for each measure</b>	<b>-</b>	<b>2</b>	<b>4</b>	<b>3</b>	<b>2</b>	<b>(11)= 2.4</b>
<b>How often does (did) ADC:</b>						
Reduce Feelings that all the responsibility falls on one caregiver	0	1	2	3	4	Av.score
<b>Scores for each measure</b>	<b>-</b>	<b>2</b>	<b>1</b>	<b>6</b>	<b>2</b>	<b>(11)= 2.4</b>
Reduce feelings of Fear about the future regarding your relative	0	1	2	3	4	Av.score
<b>Scores for each measure</b>	<b>2</b>	<b>3</b>	<b>2</b>	<b>3</b>	<b>1</b>	<b>(11)= 1.8</b>
Reduce Fear not being able to continue caring for your relative	0	1	2	3	4	Av.score
<b>Scores for each measure</b>	<b>2</b>	<b>3</b>	<b>3</b>	<b>2</b>	<b>1</b>	<b>(11)= 1.7</b>
Reduce the Wish to leave the care of your relative to someone else	0	1	2	3	4	Av.score
<b>Scores for each measure</b>	<b>3</b>	<b>3</b>	<b>3</b>	<b>2</b>	<b>-</b>	<b>(11)= 1.4</b>
Reduce dependency on you as the caregiver?	0	1	2	3	4	Av.score
<b>Scores for each measure</b>	<b>3</b>	<b>4</b>	<b>1</b>	<b>3</b>	<b>-</b>	<b>(11)= 1.4</b>
<b>Total Score 40.3 indicating Moderate to High Reduction of Burden</b>						

**Please rate your overall level of reduction of burden in caring for your spouse/relative/care recipient:** (0) No reduction of burden at all (1) Mild reduction of Burden (2) Moderate reduction of Burden (3) High reduction of Burden (4) Very high reduction of Burden

**Interpretation:**

- a. No or minimal reduction: 0 to 20
- b. Mild to moderate reduction: 21 to 40
- c. Moderate to high reduction: 41-60
- d. high to very high reduction: 61 to 88

**Appendix C: Condensed-Average Scores Indicating Level of Caregiver Strain**

**Dimensions for the Caregiver Assessment**

Enough Time to maintain control and address responsibilities	<u>Av. score</u> <b>1.9</b>
Uncertainty caring for loved one	<u>Av. score</u> <b>1.5</b>
Feelings of strain	<u>Av. score</u> <b>2</b>
Negative impact on life	<u>Av. score</u> <b>1.9</b>
Fear that your care is not good enough	<u>Av. score</u> <b>2.6</b>

**Appendix D: Condensed-Average Scores Indicating Caregivers Who Received Relief, Alleviation of Strain via Use of the ADC**

**Dimensions for ADC assessment**

How much relief does ADC provide for self and from responsibilities?	<u>Av. score</u> <b>2.7</b>
How far does ADC reduce feelings of uncertainty?	<u>Av. score</u> <b>3</b>
How much strain does ADC reduce?	<u>Av. score</u> <b>2.7</b>
Positive impact on life	<u>Av. score</u> <b>2.3</b>
How far does ADC reduce your fear that your care is not good enough?	<u>Av. score</u> <b>1.7</b>

**Appendix E: Assessing the Impact of Adult Day Care Services on Caregivers Project**

**CONSENT FORM**

FAU- Masters of Social Work Team is conducting an assessment of an Adult Day Care Center. The goal is to learn how the ADC impacts a caregiver's life and alleviates his/her stress level. We would achieve this by asking you to fill out a simple survey.

Any information provided will be kept confidential. No names or personal information will be requested.

All collected information will be kept in locked files. The interview instruments will have only a reference number– all statements will be destroyed 2 weeks after the research is completed.

Participation in this evaluation project is completely voluntary. You may refuse to answer any questions you do not wish to answer. You may terminate the interview at any time.

If you have any questions regarding this evaluation feel free to contact the FAU- Masters of Social Work Team at 954-304-5223 Lee Duncan.

I have read and understood this Consent Form and I agree to be interviewed.

I hereby give permission to use the statements I have made only for the purpose of this study: "Assessing the Impact of Adult Day Care Services on Caregivers" led by FAU- Masters of Social Work Team – Lee Duncan, Rosena Tanis, and Joan Bowla

Signature \_\_\_\_\_ Date \_\_\_\_\_

We thank you for your input in the project!