



Measuring Outcomes of Community Integration Programs: A Case Study



Baycrest Enriching Care
Enhancing Knowledge
Enlightening Minds

Kunin-Lunenfeld Applied Research Unit

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Introduction

Measuring outcomes of services designed to support long-term community participation in survivors of ABI is complicated by the heterogeneous nature of participation. Many survivors require services throughout their lifespan. Thus evaluations need be able to detect (1) positive change, (2) maintenance of gains, (3) monitoring for changes in functional abilities with major life events, and (4) decline in functional status with age. Further, outcomes need to be evaluated for the caregivers of survivors and for satisfaction with services.

These needs were taken into account in this pilot study of the CHIRS Aging at Home program.

The objectives of this pilot study were:

- to evaluate the utility of selected mood and quality of life outcome measures;
- to evaluate the feasibility of our measurement strategy.

Methods

Participants:

32 families were offered services, 28 entered the program (3 without family caregivers).

Procedure:

1. Assessments conducted at intake and after a mean of 8.2 mos of service delivery.
2. Satisfaction survey conducted after 12 mos of service delivery.

CHIRS Aging at Home Program

•Goals:

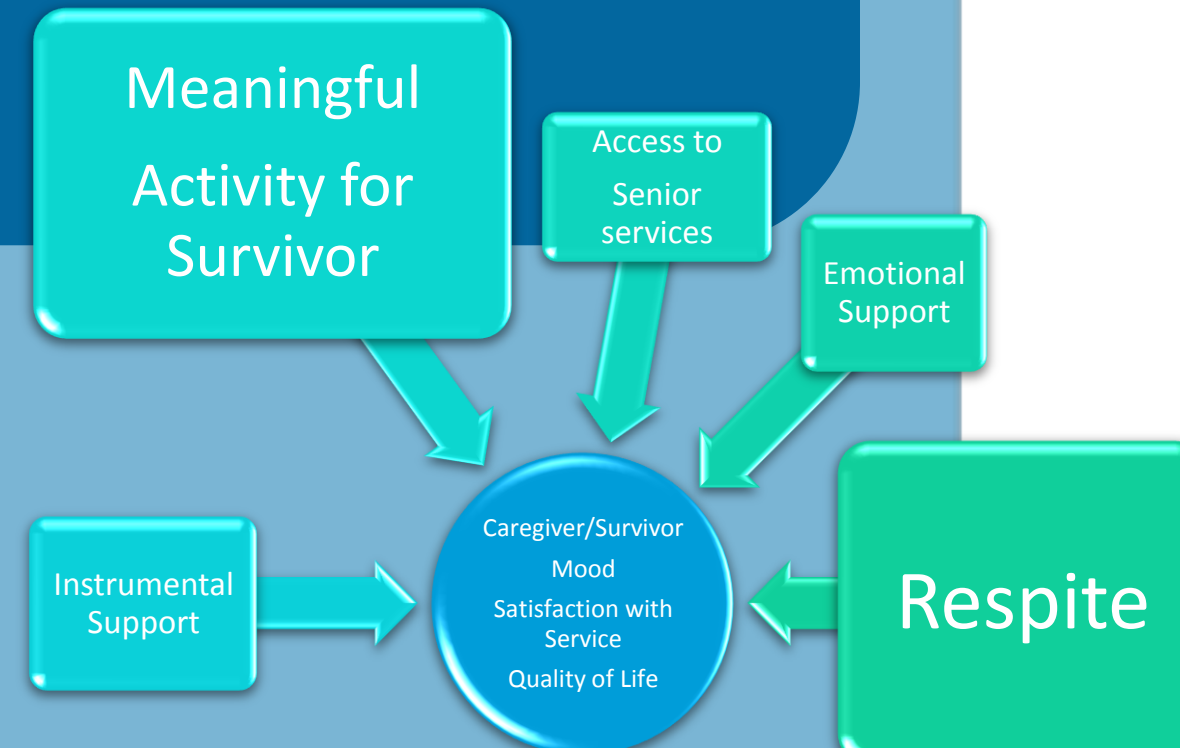
- To improve the quality of life for aging caregivers and their adult family members with ABI;
- To prevent caregiver and survivor morbidity.

•Admission Criteria:

- Survivor or caregiver aged 50+ & living in the community

•Services Available

- 0-4 hrs 1:1 time including:
 - Case management & referral
 - Setting and addressing individualized goals
 - Access to CHIRS clinical, recreational & vocational programs.



Note: Size of box reflects magnitude of hypothesized service need.

Measures

Measure	Respondent		
	Survivor	Caregiver	Support worker
Center for Epidemiological Studies-Depression CES-D (Radloff, 1977)	✓	✓	
Neurobehavioural Functioning Inventory NFI** (Kreutzer, Seel & Marwitz, 1999)	✓	✓	
Mayo-Portland Adaptability – 4 MPAI-4 (Lezak & Malec, 2005)	✓	✓	✓
Satisfaction with Life Scale SWLS (Diener, Emmons, Larsen & Griffin, 1985)	✓		
Zarit Burden Interview ZBI (Bédard, Molloy, Squire, Sacha, Dubois, Lever & O'Donnell, 2001)		✓	
Family Need Questionnaire FNQ (Kreutzer, 1988)	✓		
Disability Rating Scale DRS (Rappaport, Hall, Hopkins, Beliza & Cope, 1982)			✓
Satisfaction with Service**	✓	✓	

Results

Survivors					
	N	Min	Max	Mean	SD
Age	28	20	63	44.89	12.99
Years since injury	28	2	36	13.96	10.29
DRS	28	11	28	19.11	4.60
Gender	24 Males & 9 Females				
Etiology	TBI-12; Stroke-4; Tumor-6; Anoxia-3; Infectious-2; Surgical-1				

Caregivers			
Relationship to Survivor			
Spouse		6	
Parent		10	
Sibling		2	
Child		2	

• All 15 Caregivers who completed the CES-D scored above the cut-off of 16 used to identify potential depression (Mean=36.7, SD = 8.1).

• Nine of the 11 caregivers who completed the Brief Zarit Burden Interview scored above the suggested cut-off of 17 for "considerable burden". (Bedard et al., 2001)

Zarit Burden Interview					
	N	Min	Max	Mean	SD
ZBI Brief*	11	9.00	35.00	23.36	8.32
ZBI Screen*	16	4.00	14.00	9.06	2.93

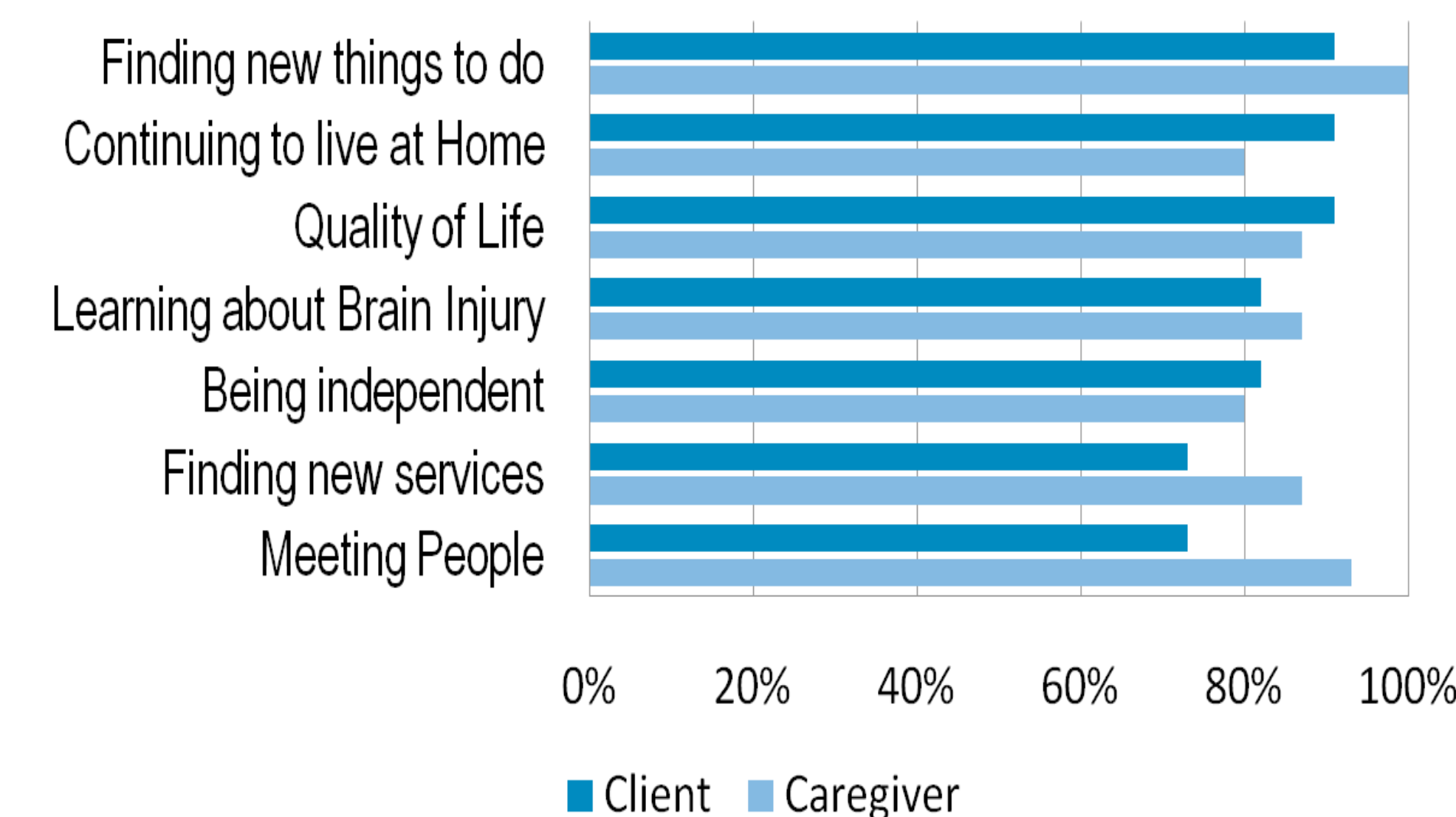
Cut-off for ZBI Brief=17, ZBI Screen = 8.

Results

Family Needs Questionnaire		
Top 5 Unmet Needs	% Endorsed	
	Not Met	Partially Met
1. Have help keeping the house	62.5	12.5
2. Get a break from problems or responsibilities	52.6	31.6
3. Help preparing for the worst	47.1	29.4
4. Have time for my own needs, job or interests	36.9	42.1
5. Discuss my feelings about the patient with someone who has gone through the same thing	47.1	23.5

Satisfaction Survey

Does the help you were provided with Contribute to.....



Most Appreciated

- Respite
- Productive Activity
- Emotional Support
- Health Care Referrals
- Respectful, compassionate care

Most Desired

- Residential Respite
- Vocational Placements

Descriptive Statistics for Depression & Satisfaction with Life

	n	Min	Max	Mean	SD
CES-D Intake	20	19.00	58.00	37.65	9.31
CES-D Follow-up	16	22.00	50.00	35.31	7.83
SWLS- Intake	24	5.00	33.00	17.33	7.39
SWLS- Follow-up	20	10.00	32.00	19.65	6.33

Mood: There was a trend toward reduced depression from intake to follow-up in survivors. 3 off the survivors with complete data improved by 10 points or more. All explained the change by reporting a dramatic increase in productive activity.

SWLS: 3 clients with complete data showed a positive change of 8 or more (1 SD for relevant samples) on the SWLS. Of these, only one had a change of 10 or more on the CES-D.

Intake – Follow-up Comparisons

	Paired Differences		t	df	Sig. (2-tailed)
	Mean	SD			
Participation Intake*					
Participation Follow-up	1.43	6.65	.80	13	.44
SWL Intake- SWL Follow-up	-2.84	6.45	-1.92	18	.07
CESD Intake – CESD Follow-up	3.86	7.63	1.89	13	.08

Notes: *MPAI – 4 participation professional ratings. Higher scores = greater impairment. **Satisfaction With Life, higher scores indicate greater satisfaction. **CES-D, higher scores = greater depression.

Discussion

- Implementing an evaluation strategy of the Aging at Home Program required significant modification. Future data collection will involve abbreviated assessments and scheduled respite for survivors to help reduce missing data and delay of assessment past planned time-points.
- Although changes were seen on some measures (e.g., SWLS), others did not appear to capture the impact of services – e.g., CES-D. Other measures will be investigated that may be more sensitive to change.
- Participants in the Aging at Home Program reported similar needs to normative samples with the exception of expressing a greater need for personal resources respite care. This was consistent with our pre-service needs assessment.
- As well, the SWLS did show change in some individuals, is easy to administer and is considered to represent a facet of QOL that is modified by life circumstance. Thus, it will be maintained in the assessment group.
- The MPAI-4 participation scale did not show a change. We are investigating other participation measures that may be more sensitive while maintaining this to ensure we track survivors' functional status.
- Our most useful measures of outcome continue to be goal attainment and self-reported satisfaction with services.