

DEMENTIA, CAREGIVING AND INNOVATION

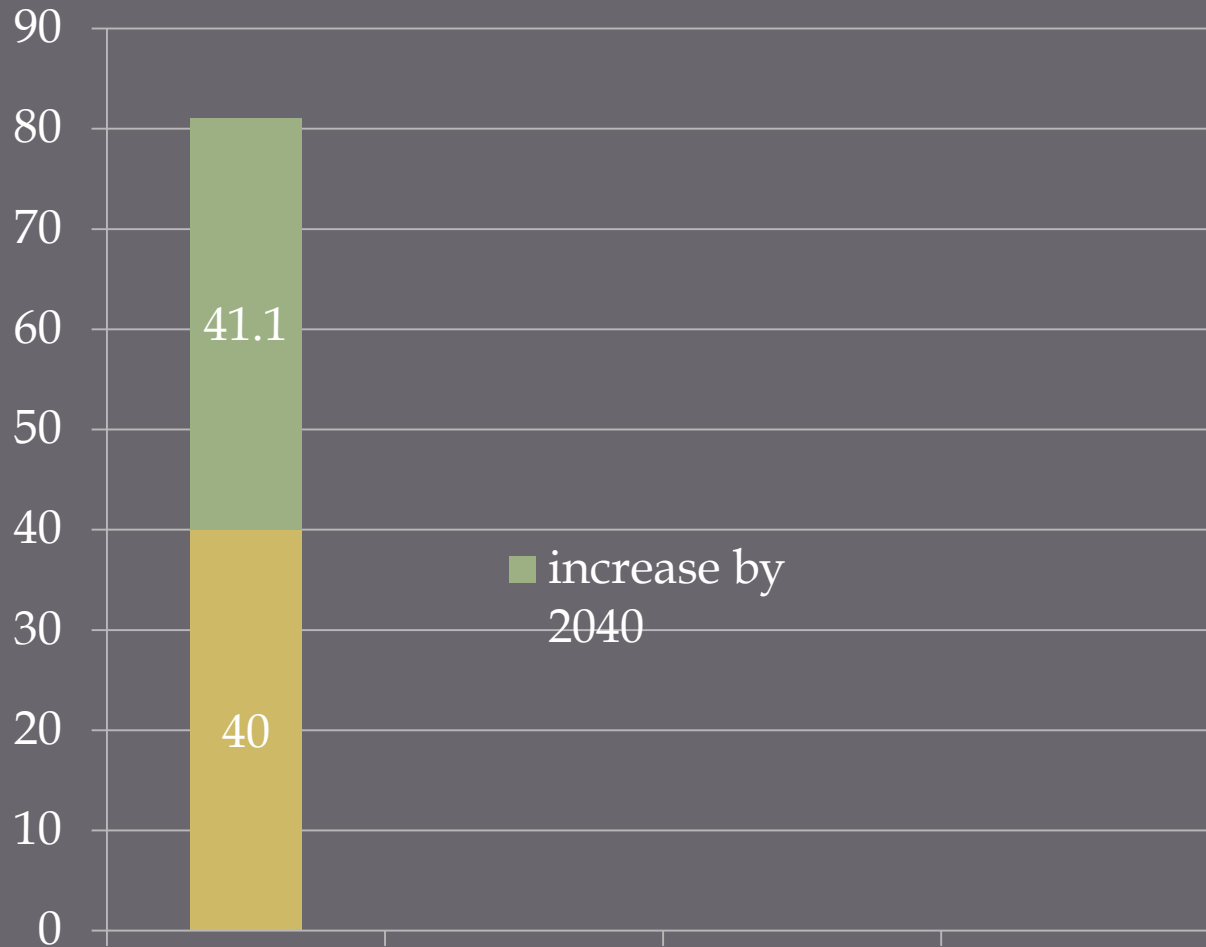
Joel Sadavoy MD, FRCP, Founder Geriatric Psychiatry
Professor of Psychiatry and Pencer Chair in Applied
General Psychiatry, Director Reitman Centre and Head
Geriatric Psychiatry Mount Sinai Hospital and
University of Toronto



IFA World Congress
June 10 2014

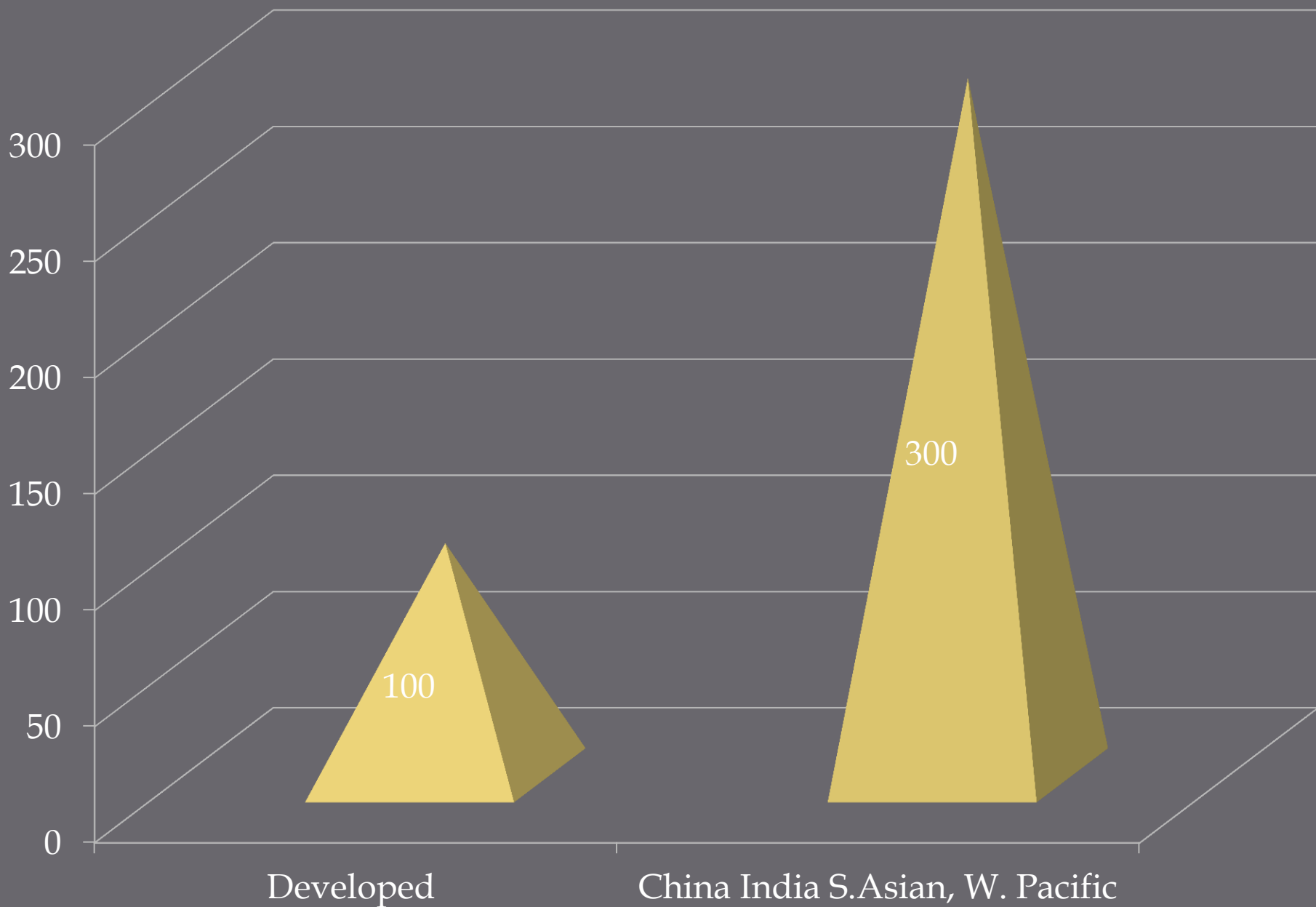
Who are Family Caregivers

- ▣ Most people with dementia live in the community (USA 70% to 81%)³⁻⁶
- ▣ 75% of care is provided by family and friends.⁵ i.e. Mostly female (USA 60%). In India 24% of caregivers were daughters-in-law).
- ▣ Developed countries.¹ the typical profile similar to USA, BUT
- ▣ the proportions of female caregivers higher (mean of 78%, range from 59% in China and SE Asia to 95% in Nigeria),
- ▣ persons with dementia in the developing world live in much larger households with extended families



change in
world
dementia
rate 2014-
2040
(Millions)

% rise in world dementia rates by regions 2001-2040



4 Key Domains of Successful Caregiving



**Practical
and
professional
support
and resources**



**Knowledge
of the
disease,
treatment,
and
resources**



**Effective
caregiving &
problem
solving
skills**



**Emotional
wellbeing**

Family Caregivers in Dementia

▣ Annual replacement /imputed costs for unpaid caregivers:

- **Canada 2009 CAD \$25-\$31 billion**

Hollander et al 2009

- United Kingdom 2007 - **£87 billion** Buckner and Yeandle 2007
- United States 2006 - **US\$354 billion** Gibson and Houser 2007
- Australia 2005 - **A\$30.5 billion** Access Economics Pty Limited 2005

- **Essential part of the health care infrastructure**

Employed Family Carers

Work/life conflict of carers in the workforce negatively impacts the social and economic bottom line & the Workplace

- Absent more often from work 25%
- Reduced productivity at work 22%
- Increase their use of employee benefits 21%
- Reduced work hours 19%
- Turned down promotions 20%
- Reported emotional effects of caregiving 63%

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Community-Based Clinical Care for CARERS

A comprehensive response to needs of carers

THE CYRIL AND DOROTHY JOEL AND JILL REITMAN CENTRE FOR ALZHEIMER'S SUPPORT AND TRAINING AT MOUNT SINAI HOSPITAL



Human Resources and Skills Development Canada

Ressources humaines et Développement des compétences Canada

This project is funded in part by the Government of Canada

- ▣ A 10 week program delivered in small groups of spouses or children of people with dementia
- ▣ Identify specific problems of each caregiver
- ▣ Coached by trained group leaders to Address them using problem solving technique or simulation.
- ▣ Understand emotions and deal with them in the group which supplies feedback and support.

Clinical Outcomes

Eight pre/post measures evaluate the CAREERS program's effect on carers' psychological functioning, caregiving skill sets and stress coping styles:

- **Coping** Inventory in Stressful Situations (CISS)
- Care-giving **Competence**
- Geriatric **Depression** Scale
- Short Zarit **Burden** Interview
- **Mastery**
- **Overload**
- **Role Captivity**
- (Revised Memory and Behavioural Checklist)

CARERS Program Reitman Center Results (N=72)

**Coping, Competence, Depression and Role Overload:
clinically and statistically improved**

Measures	N	Mean Scores Pre- and Post-Intervention		Change from Baseline	
		Baseline \pm Std. Dev	Post-Intervention \pm Std. Dev	Mean Change \pm Std. Dev	Significance
CISS A (-) ^a	68	40.59 \pm 9.70	40.49 \pm 10.26	-1.03 \pm 5.97	NS (p = 0.887)
CISS E (-)	68	39.65 \pm 11.21	37.28 \pm 10.49	-2.37 \pm 6.73	p < 0.01* (p = 0.005)
CISS T (+)	68	57.72 \pm 9.02	56.76 \pm 8.94	-0.96 \pm 7.99	NS (p = 0.327)
Competence (+)	70	12.14 \pm 2.12	13.40 \pm 2.07	1.26 \pm 1.92	p < 0.0001*
Geriatric Depression Scale (-)	64	4.70 \pm 3.89	4.03 \pm 3.70	-0.67 \pm 2.63	p < 0.05* (p = 0.045)
Mastery (-) ^b	70	14.76 \pm 3.69	14.51 \pm 3.32	-0.24 \pm 2.54	NS (p = 0.426)
Overload (-)	67	9.93 \pm 2.67	9.37 \pm 2.71	-0.55 \pm 2.07	p < 0.05* (p = 0.032)
Role Captivity (-)	69	7.42 \pm 2.68	7.29 \pm 3.23	-0.13 \pm 2.20	NS (p = 0.623)
Zarit Burden (-)	67	19.87 \pm 10.61	19.04 \pm 9.54	-0.82 \pm 6.87	NS (p = 0.332)
<i>RMBC</i>					
Avg Reaction per Memory (-)	69	1.49 \pm 0.97	1.30 \pm 0.82	-0.19 \pm 0.85	NS (p = 0.065)
Avg Reaction per Depression (-)	69	1.73 \pm 1.15	1.90 \pm 0.96	0.17 \pm 0.94	NS (p = 0.134)
Avg Reaction per Disruption (-)	69	1.72 \pm 1.08	1.78 \pm 1.18	0.062 \pm 1.45	NS (p = 0.723)
Avg Total Reaction per problem (-)	69	1.70 \pm 0.77	1.65 \pm 0.73	-0.053 \pm 0.71	NS (p = 0.538)

Notes: ^aThe plus or minus sign following each measure indicates the direction of change sought through the intervention. For example, a decrease in Emotion-focused coping style or an increase in the Competence score would indicate good outcomes.

^bMastery score was calculated using a negative-oriented scale (i.e. response to positively phrased questions were reverse-coded). Thus, a decrease in Mastery score indicates improvement.

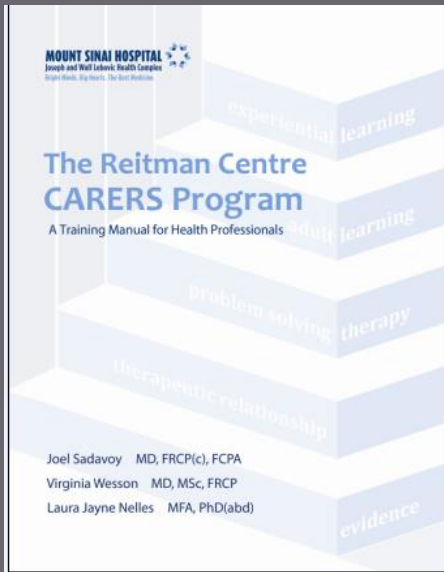
Legend: Competence = Pearlin's Competence Scale; CISS A = Coping Inventory of Stressful Situations (Avoidance-Oriented); CISS E = Coping Inventory of Stressful Situations (Emotion-Oriented); CISS T = Coping Inventory of Stressful Situations (Task-Oriented); GDS = Geriatric Depression Scale (GDS-15); Mastery = Pearlin's Mastery Scale; Overload = Pearlin's Overload Scale; Role Captivity = Pearlin's Role Captivity Scale; RMBC = Revised Memory and Behavior Problem Checklist; Avg Reaction per Memory = Average Reaction per Memory problem; Avg Reaction per Depression = Average Reaction per Depression problem; Avg Reaction per Disruption = Average Reaction per Disruption problem; Zarit Burden = Zarit Burden Index (ZBI-12)

Satisfaction Results (N=72)

Satisfaction, Met Needs and Helpfulness > 95%

	Agree (%)	Neutral (%)	Disagree (%)
Overall Feedback:			
Overall, I was disappointed with the program	1.4	4.2	94.4
Overall, the program was helpful to me	98.6	1.4	0
Overall, the program addressed my needs	94.4	5.6	0
Overall, I was satisfied with the program	95.8	4.2	0
I would recommend this program to someone else	97.2	2.8	0
Clinical Components:			
The program enhanced my practical skills	87.5	9.7	2.8
The program improved my coping and problem-solving skills	95.8	1.4	2.8
The program improved my ability to manage difficult emotions	91.7	6.9	1.4
Following the program, I am more confident dealing with care-giving challenges	90.3	9.7	0
Following the program, I am more depressed and anxious	4.2	15.3	80.6
I received adequate professional support	95.8	2.8	1.4
I found the focus on emotions in care-giving to be helpful	93.1	5.6	1.4
Setting Components:			
The size of the group was appropriate	94.4	0	5.6
I did not find it helpful to include people in the same group who are dealing with different stages of the illness	4.2	13.9	81.9
The length of the program was adequate	79.2	4.2	16.7
The length of each group session was adequate	88.9	6.9	4.2
On Simulations:			
I did not find the simulations useful	11.1	2.8	86.1
I found participating in the simulations stressful	25.0	18.1	56.9
Practicing the same simulation several times was not helpful	5.6	20.8	73.6
The simulations accurately portrayed the problems I am encountering at home	83.3	6.9	9.7

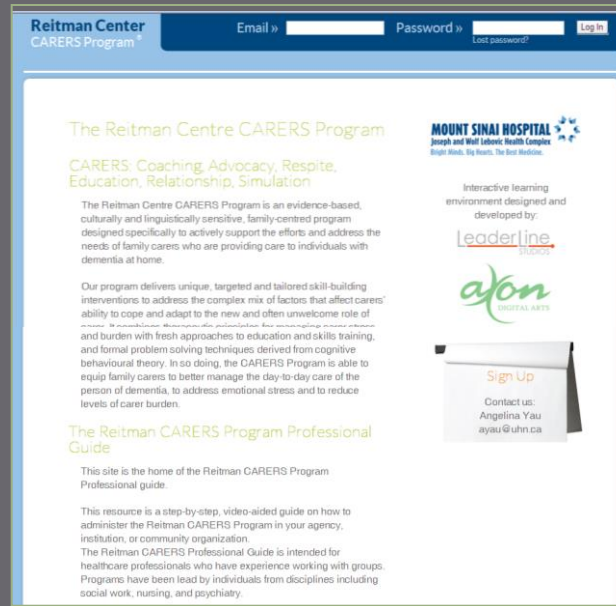
Knowledge Exchange: Educational Tools Suite



Paper-based CARERS Program Manual

Comprehensive training manual for health professionals to deliver CARERS Program

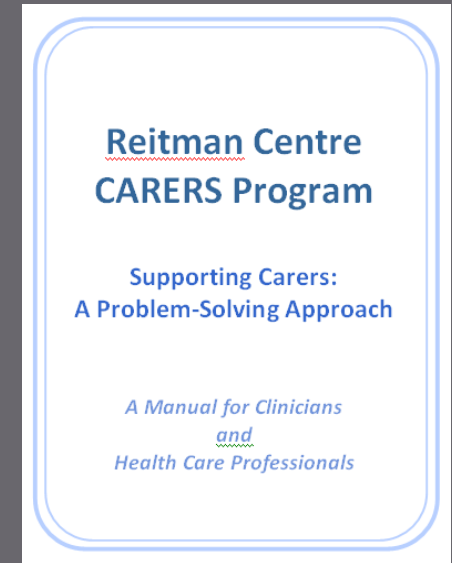
implementation guide translated into Chinese



Web-based CARERS program e-learning tool

Train health professionals in theory and practical application

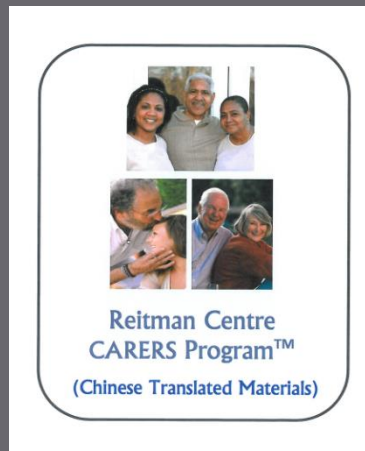
Interactive with self assessment



Paper-based class-room presentation

Focuses on "Problem-solving Techniques" and "Simulation"

For specialized MH & complex care health professionals



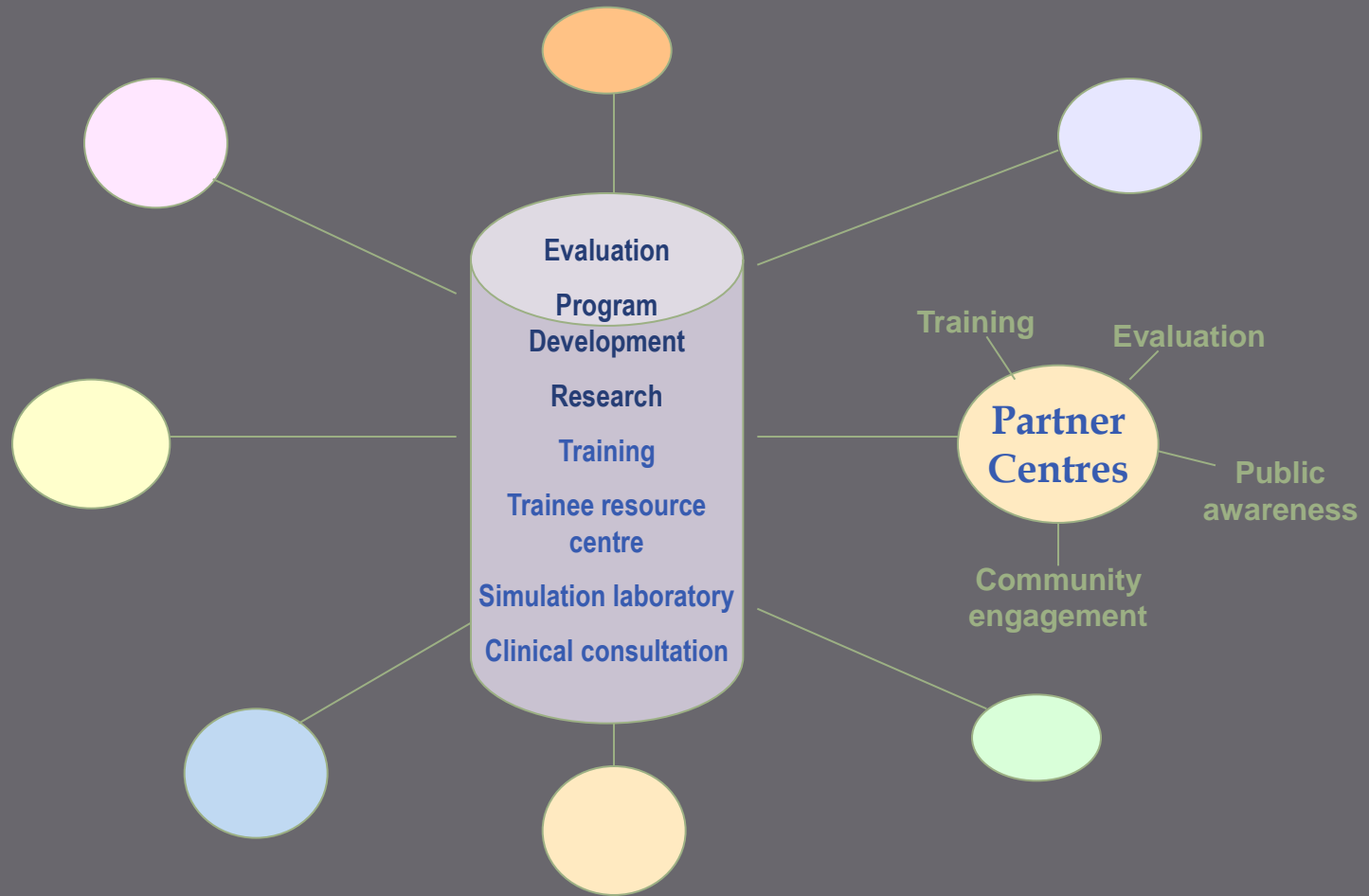
Dissemination of RC Program

- ▣ Culturally diverse communities (Chinese Portugese, Jewish)
- ▣ Local, national (6 new RC programs)
- ▣ Innovative location (Faith based Institution)

Training for Professionals in the Community

- ▣ Community Care coordinators (200 in Toronto)
- ▣ Provincial Role-out in Ontario (pending)

Now Positioned to be a Catalyst for System Change (Ontario Model)



Center of Excellence



Satellite sites; e.g. ethnic communities, remote and rural areas, cross other provinces

The Need to Expand the CARERS Program to Working Carers

Work/life conflict of carers in the workforce negatively impacts the social and economic bottom line & the Workplace

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The Reitman Centre Working Carers Program

A government, public & private partnership

Funded in part by the Government of Canada's Social Development Partnerships Program



MOUNT SINAI HOSPITAL
Joseph and Wolf Lebovic Health Complex
Bright Minds. Big Hearts. The Best Medicine.



The National Reitman Centre Working CAREERS Program

An innovative partnership model among Government, Not-for-profit and Corporate sectors

ESD Canada- \$2.84 million

- Tailored to the needs of paid working carers to enhance and sustain their labour market participation
- 5 year project with view of sustainable delivery of The Program through EAP partners after 5 years



THANK YOU

Questions?

How to help ?

- ▣ Need for interventions that are effective, targeted and **specific** but that can be brought to large **scale**
- ▣ very few and most have been research based not embedded in a service system and therefore temporary.

Care recipient and Carer are a unit

- ▣ “Patient and caregiver characteristics are both important determinants of long-term care placement for patients with dementia.
- ▣ Interventions directed at delaying placement,need to take into account the patient and caregiver as a unit”

Yaffe, K. et al. (2002). Patient and caregiver characteristics and nursing home placement in patients with dementia. *JAMA*, 287, 2090-2097

Vision : A Model for Change

Scaling
System Capacity
Expand Partnerships
Expand Multicultural Outreach
Evaluation Measures/Research
Expand use of Technology

BRINGING THE MODEL TO SCALE

NATIONAL WORKING CAREGIVER EFFICACY STUDY

Lead by Reitman Centre

references

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- ▣ 3. Alzheimer's Association and National Alliance for Caregiving. *Families care: Alzheimer's Caregiving in the United States*. Chicago, IL: Alzheimer's Association and National Alliance for Caregiving; 2004
- ▣ 4. Office for National Statistics. *Focus on Older People*. Newport, UK: Office for National Statistics; 2005
- ▣ 5. Schulz Ft., Martire LM. Family caregiving of persons with dementia: prevalence, health effects, and support strategies. *Am J Geriatr Psychiatry*. 2004;12:240-249
- ▣ 6.. Census Bureau. *65+ in the United States: 2005*. Washington, DC; 2005