

**Consumer and Carer Consultation
Workshop Report
15 June 2005 Mt Isa QLD**



**Centre for Rural and Remote Mental Health –
Queensland
Implementation Project**

Cover page

These symbols were how participants and facilitators presented themselves to the group at the beginning of the workshop:

- ✚ egg – fertility in all areas of life
- ✚ smiley face
- ✚ clown
- ✚ man with sore leg
- ✚ smiley face with ears – listening
- ✚ man looking in each direction for answers
- ✚ mind – always trying to think
- ✚ face - confused
- ✚ seeking help for myself and others like me
- ✚ star – searching
- ✚ man with load - trying to push QLD Health off my back
- ✚ dot in middle of other consumers trying to help
- ✚ thinker – looking for clear ideas
- ✚ happy face – happy to be here
- ✚ person drowning
- ✚ unashamedly, primarily a mother
- ✚ stretching the boundaries
- ✚ person interested, received help, helping others
- ✚ face in box – general attitude to mental health
- ✚ football – participation in whatever you do
- ✚ cross & airwaves – clergyman & broadcasting – 2 life passions, life influenced by son
- ✚ face crying – listening, despairing, finding answers
- ✚ face with question mark – have lots of questions & answers
- ✚ Aboriginal symbols – people sitting around talking
- ✚ question mark – looking for answers
- ✚ changing shapes – versatile, changing roles
- ✚ open door

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ACKNOWLEDGEMENTS

- Department of Health and Ageing which funded the workshop;
- Simon Bridge consumer member of the CRRMH-Q implementation committee for his advocacy for participation of consumers particularly those who are in the workforce;
- Mental Health Association (Queensland) Susan Stephenson and Andy Crompton for their contribution to the program and facilitation;
- Terry Lees Rotary Mt Isa
- Generalist and mental health professionals in rural and remote areas across the state who informed consumers and carers about the workshop and enabled contact with the CRRMH-Q project;
- Royal Flying Doctor Service Mt Isa for provision of the venue, facilities and staff;
- and to all those consumers and carers who gave their time to travel or be linked in by telephone to participate with enthusiasm and openness.



L-R : Terry Lees from Rotary Mt Isa with Henry and Gladys Callope

BACKGROUND

The Centre for Rural and Remote Mental Health-Queensland project is a statewide initiative directed towards improving the mental health people in rural and remote areas of Queensland. The project aims to establish a Centre which will focus on service enhancement, education and training, policy and program development, and research and evaluation with information communication technology supporting all areas of activity. The Royal Flying Doctor Service (Queensland Section), Rotary, James Cook University, Comalco, Queensland Health University of Queensland, Wu Chopperen Health Service, and the Australian Government Department of Health and Ageing (DoHA) are collaborating in the current one year CRRMH-Q implementation phase.

Consumer and carer participation is integral to improvements in mental health care however challenges are presented by the stigma and the reduced anonymity often experienced in rural and remote areas. While there has been some consumer and carer participation during the earlier feasibility stage, and the current CRRMH-Q implementation project committee has consumer membership, more targeted and extensive consultation with a broader geographical range of consumers and carers was essential to ensure that meaningful participation continues to inform the development and statewide activities of the Centre. Special funding from the DoHA enabled the CRRMH-Q implementation project to hold a consultation workshop. The purpose of the workshop was to promote the active participation of rural and remote consumers and carers in the CRRMH-Q development and activities through serving as a starting point for establishment of a broader reference network to inform the CRRMH-Q project on an ongoing basis.



L-R: Roanne Sanders, Petina Bonato, Julie Angus and Phillip Conti.

THE WORKSHOP

The one-day consultation workshop was held at the Royal Flying Doctor Service Visitors Centre in Mt Isa on 15th June 2005 (see Appendix 1: Workshop program). In total twenty-one mental health consumers and carers from rural and remote areas across Queensland participated in the workshop (see Appendix 2: Workshop participants). Twelve people identified primarily as consumers and nine as carers and 4 out of 21 stated they were both carers and consumers. Five participants were Indigenous and another four confirmed Indigenous participants (all from remote locations) were unable to attend due to circumstances beyond their and the organisers control. Another fourteen people joined a one and a half hour teleconference consultation held on the same day. The purpose of the teleconference was to include people who were working and for other reasons unable to travel to Mt Isa (see Appendix 3: Teleconference participants). Those who participated in the workshop were from Cairns, Mt Isa, Townsville, Charters Towers, Toowoomba, Innisfail, Longreach, Winton, Walkamin, Mornington Island and Normanton. The teleconference expanded the statewide coverage to Mackay, Roma, Bamaga, Gympie and Quilpie.

Participants were recruited through the generous assistance of health practitioners and non government agency staff who work with mental health consumers and carers in rural and remote areas of Queensland. Particular effort was made to include culturally and linguistically diverse and Indigenous consumers and carers. Locating the workshop in Mt Isa facilitated the attendance of Aboriginal people from that region but efforts to attract any CALD consumers and carers were unsuccessful despite the active cooperation of the Queensland Transcultural Mental Health Network and a regionally based migrant resource service with a mental health support worker.

Workshop planning and facilitation involved a cooperative partnership between the Royal Flying Doctor Service Mt Isa Base, the Mental Health Association Queensland and the CRRMH- Q Implementation Project. . While information about mental health care in rural and remote areas in Australia is very limited, there is even less known about informal community care and self care from consumers' and carers' perspectives. The consultation focused on priority issues in informal community care and self care in rural and remote areas. The workshop concluded with an open discussion about the CRRMH- Q and the means to make it effective from the perspective of consumers and carers.

In addition to documentation of the workshop and teleconference proceedings an evaluation form was distributed. A total of 21 feedback forms were collected which included information from 8 consumers, 7 carers and 4 people who identified as both consumers and carers. Five of the 21 identified as Indigenous, 7 as non-Indigenous and the remainder did not identify.



L-R
Gordon Burley
Joel ah Kit
Susan Sewter
Phillip Conti
Elizabeth Cowper



Facilitators: Liz Kyle RFDS Mt Isa, Andy Compton MHAQ, Terry Hill RFDS Mt Isa



L-R: Petina Bonato, Gladys Callope, Henry Callope, Karen Richardson-Johnson, Brenda Musemeci, Rafe Picton



L-R: Rafe Picton, Elizabeth Cowper and Ann Kreger

PRIORITY AREAS FOR ATTENTION BY CRRMH-Q



Key ideas emerging from the consumers and carers were:

- In order to address the community-based supports for consumers (place, persons, activities...) the CRRMH-Q should address the preconditions for same (collating information and developing needs analysis, advocating for policy change and developing specific programs).
- Ensure that health and allied care are committed not only to a recovery framework for consumers but to an orientation to growth through illness and wellness.
- CRRMH-Q should consider and address ways in which generational change in rural and remote communities, particularly Indigenous communities, undermines the roles and responsibilities of adults and elders, and the salience of traditional roles and processes.
- Examine the relationship between stigmatisation, exclusion and pressures to conform affecting the wellbeing of mental health consumers in rural and remote communities.
- Address needs of consumers and carers through a community-orientation – What are the preconditions and supports necessary to make communities inclusive of mental health consumers in all aspects of community life?
- Identify and define the particular circumstances and needs of different rural and remote settings and communities.
- Provide a mechanism to support communication between consumer and carer organisations throughout Queensland and to enable a statewide voice for rural and remote consumers.
- Examine the nature of social relationships and connectedness in rural and remote communities and the implications of this for the roles and

responsibilities of service providers. The limited number and density of social connections, leading to greater degrees of isolation, has implications for the consumer expectations of providers. There thus needs to be a balance that also addresses the social and privacy needs of providers.

- Consider ways in which the limited number of health service providers in rural and remote settings (thus meaning major constraints on choice) influences real and perceived power differentials between consumers/carers and providers, and problems in the therapeutic relationships arising from this.
- Given the limited support resources in rural and remote settings, consider and address the ways in which social networks fragment when someone begins to become well. By so doing, supporting the natural peer and family networks that sustain people in times of wellness.
- Develop means to utilise media in rural and remote settings to address issues relevant to health and wellbeing of consumers and carers – including stigma, positive representations etc.
- Given the opportunities of rural and remote communities in terms of size, networks etc, develop approaches to whole of community approaches to mental health promotion and prevention initiatives.
- Develop and provide appropriate resources and training in relation to mental health for workers in rural and remote non-health services – education, police, councils ...



L-R

Beryl Green Charters Towers

Susan Stephenson Mental Health
Association QLD

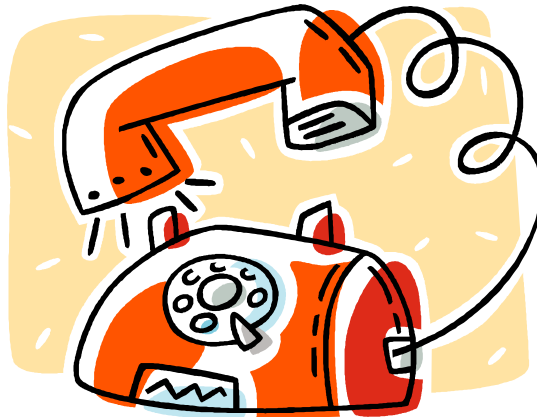


Ross Donovan- Cairns, Ernest Hunter- CRRMH-Q Committee, Peter Persons- Walkamin, Rod Savage- Townsville.

CHALLENGES FOR CONSUMER AND CARER PARTICIPATION IN THE CRRMH-Q

- In the way representation is obtained, not alienating groups– inclusive representation structures;
- Ensuring effective meaningful decision making, not token representation;
- Consulting with communities;
- Ensuring responsible and accountable reporting requirements;
- Achieving sustainable resources;
- Not being dependent on volunteerism;
- Capacity to consult broadly to enable statewide legitimate consumer representation
- Ensuring Aboriginal and Torres Strait Islander representation

THE TELECONFERENCE



Of the 14 participants in the one and a half hour teleconference nine were consumers, four were carers and one identified as both a consumer and carer. A brief overview about the CRRMH-Q project had been provided to contact people at each location. The teleconference focused on the participants' experience of informal community and self care. Time constraints limited the capacity to discuss consumer and carer participation in the CRRMH-Q.

The experience of informal community care

The majority of teleconference participants reported their informal care to arise from their immediate family (spouse, children and parents) or friends. Some participants experienced work colleagues, neighbours, people involved with their arts, sports and church activities, and community support groups (such as new age group and youth drop in centre) as informal carers.

The good things about informal community care

- knowing that people cared;
- informal carers were able to see broader view;
- informal carers were able to stay positive;
- carers picked up early warning signs;
- and the listening, openness and acceptance.

Approaches used for self care

- pacing themselves, reducing workloads
- sleep /rest /relaxation
- exercise
- listening to body / self awareness
- employment
- taking time out/respice
- learning signs of relapse
- listening to friends
- asking for help
- taking medication
- using advanced health directive
- having a wellness- recovery plan

- self education

Main areas needing improvement:

- lack of time out, respite and support for carers, risk of carer burnout
- discrimination and lack of understanding in the community and consequent fear of stigma
- better access to information and support for carers

Strategies for improvement

- increased community acceptance, practical understanding through education;
- education in schools (start when people are young)
- more support for carer families and children
- improved media coverage of mental health and illness;
- campaign media about their perpetuation of prejudice and misinformation about mental illness
- better access to employment and support at work
- improve support for changed attitudes in health practitioners
- educate health practitioners about family inclusive practices

WORKSHOP EVALUATION

Ranked issues of importance

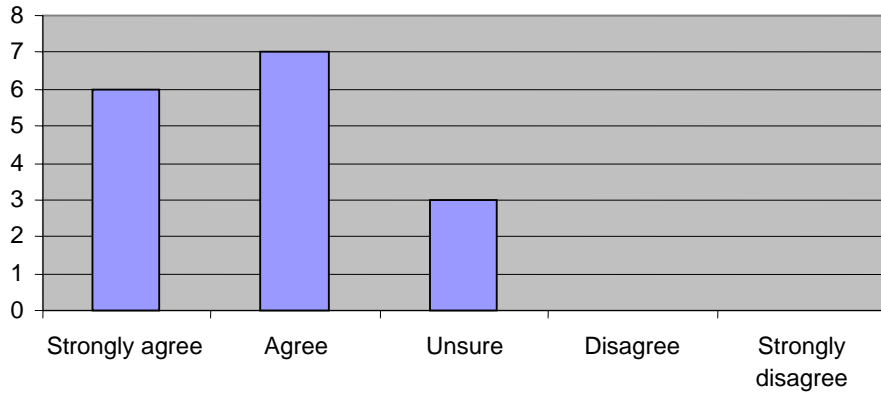
In addition to the consultation discussions with workshop participants were asked (See Appendix 5: Evaluation form page 2) to rank seven issues in order of perceived importance. Overall scores, from 1 “Most important” to 7 “Least important” were:

- | | |
|---|------------------------------------------------------------|
| 1 | mental health services |
| 2 | social isolation |
| 3 | prejudice in the community about mental health problems |
| 4 | access to general services and activities in the community |
| 5 | respite support |
| 6 | accommodation |
| 7 | employment |

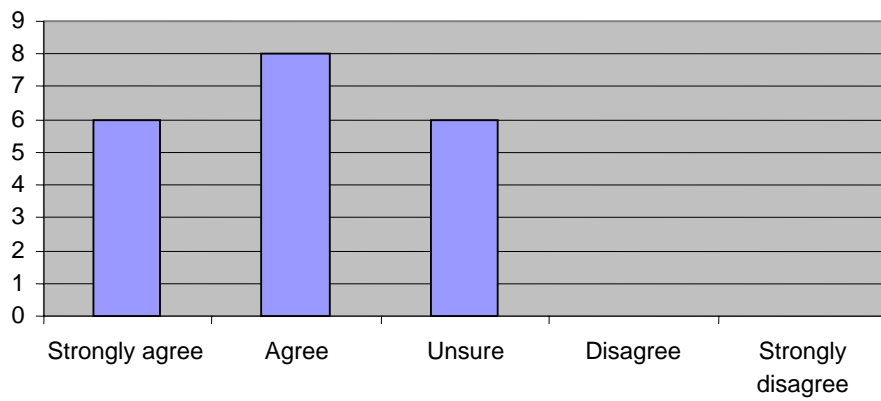
Evaluation patterns

Response to scaled statements on the evaluation/ feedback forms demonstrated the following patterns.

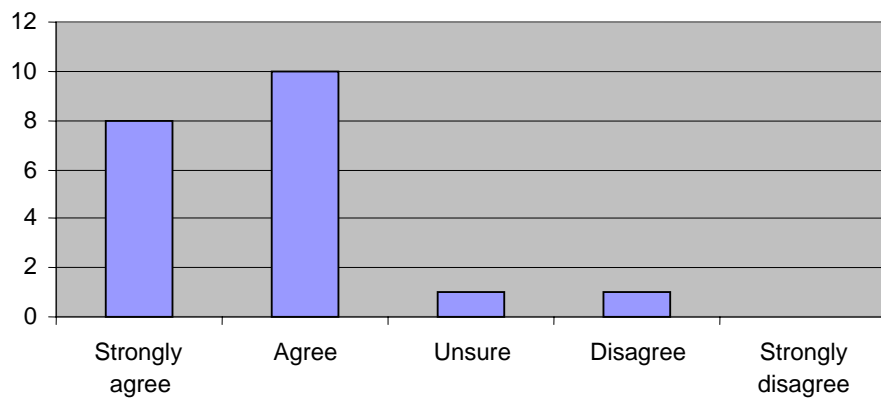
1. The program was easy to understand

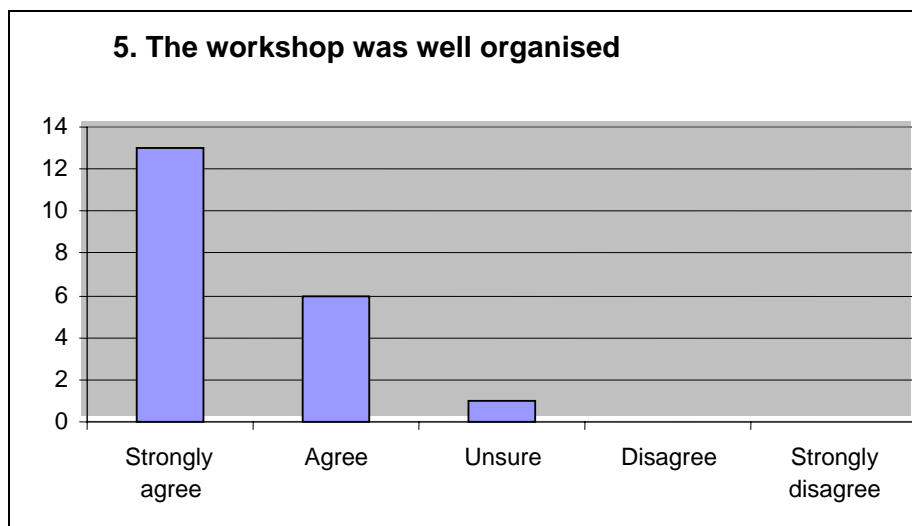
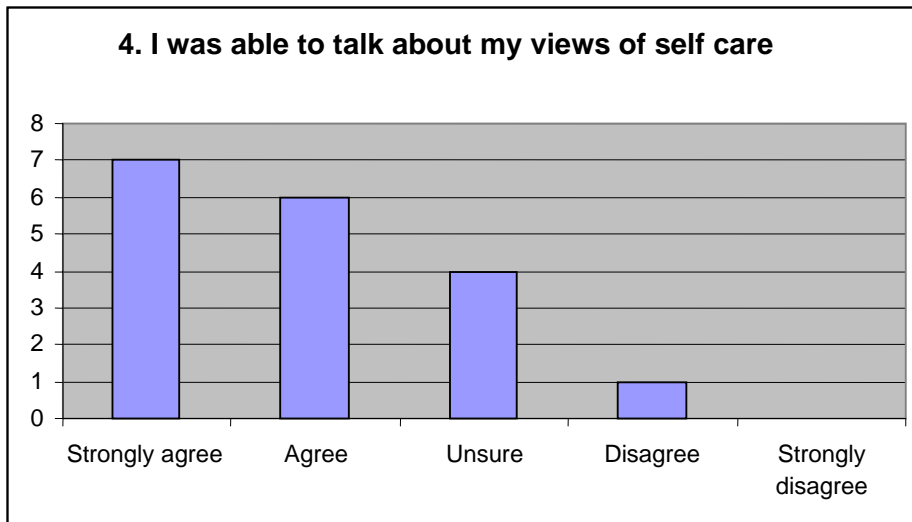


2. The workshop was relevant to me



3. I was able to talk about my views of informal care





Evaluation comments and suggestions

- Would love to attend another one
- I would like to see another workshop
- Mr & Mrs Callope would like to attend another forum in the very near future with their son
- Well done all. It's a great beginning.
- Early days I understand the need for consultation but please let us not consult too long for the people out there need this service.
- Initially the concept was a bit 'nebulous' however as the day went on I began to see how the centre could be of value and relevance , particularly as an alternative to QLD Health in influencing policy and highlighting needs. Very important and valuable idea of consumer research projects.
- The CRRMH project is a brilliant concept. The workshop was well run and it was both a pleasure and a challenge to be part of it.

- I would like to see another forum expanding on issues on Page 2. Issues raised by participants –most interesting. Thank you for the opportunity and for the knowledge I have taken away with me.
- Came to see , as consumer what the project may be providing for me and others who have or are recovering from mental illness
- Pleased to give input and being asked to attend. Sincerely hope it comes to fruition.
- Not sure of what value I was able to add, since I think I was under the wrong impression of what the outcome would be- i.e. though we'd concentrate more on WHAT the centre would DO for consumers and carers, rather than the structure of the centre- must have missed the point.
- A little bit dominated by men (paid workers).

CONCLUSION

This report demonstrates that the consumer and carer workshop achieved the intended purpose of ensuring that the Centre for Rural and Remote Mental Health –Queensland implementation and activities include meaningful rural and remote consumer and carer participation. The participant rural and remote consumers and carers expressed enthusiasm for ongoing collaboration, networking and participation. In addition to agreement to maintain a communication network between participants, a broader range of people and organisations who were unable to participate on this occasion have requested inclusion on mailing lists and involvement in future activities. The Implementation committee is consequently considering means to expand and embed consumer and carer participation in the governance and activities of the CRRMH-Q.

While the proceedings of both the teleconference and the workshop identified issues for both consumers and carers it must be noted that the issues and recommendations documented were raised from the participants as a whole and not through separate discussions. The extent to which consumers raised the need for improved support and services for carers requires noting, as do the special needs of those who are both a consumer and carer in a rural and remote area.

Appendix 1 : Workshop Program

Centre for Rural and Remote Mental Health - Queensland Implementation Project

*Collaborating organizations: Royal Flying Doctor Service James Cook University Queensland
Health University of Queensland Rotary Wu Chopperen Health Service Comalco and the
Australian Government Department of Health and Ageing*

WORKSHOP PROGRAM

Date: Wednesday 15 June 2005

Venue: Royal Flying Doctor Service
11 Barkley Highway Mt Isa

Participants: By invitation

Facilitation: Susan Stephenson Mental Health Association QLD
Andy Compton Mental Health Association QLD
Terry Lees Rotary
Terry Hill Royal Flying Doctor Service
Liz Kyle Royal Flying Doctor Service
Ernest Hunter Queensland Health / University of Queensland
Ann Kreger CRRMH-Q project

8:30 Welcome by Traditional owner – Isabelle Holt

Introduction – Ernest Hunter, Ann Kreger & Susan Stephenson

- Brief overview of the history and development of the CRRMH-Q project
- Purpose of the workshop
- Informal community care and self care

09:30 Discussion and Feedback

10:00 MORNING TEA

10:30 Facilitated Small group discussion

- **INFORMAL COMMUNITY CARE:** Important issues for consumers and carers in rural and remote areas

11:30 Summary: key issues for informal community care in rural and remote areas

12:15 PRESENTATION OF CERTIFICATES FROM MHAQ ADVOCACY COURSE

12:30 LUNCH

1:15 Facilitated Small group discussion

- **SELF CARE:** Important issues for consumers and carers in rural and remote areas

2:15 Summary: key issues for self care in rural and remote areas

3:00 AFTERNOON TEA

3:30 Identification of key priorities for action in CRRMH-Q activities with Informal community care and self care

4:30 CLOSE

Appendix 2: Workshop Participants

Name	Location
Rod Salvage	Townsville
Petina Bonato	Townsville
Karen Richardson - Johnson	Innisfail
Ross O'Donovan	Cairns
Brenda Musemeci	Townsville
Rafe Picton	Toowoomba
Elizabeth Cowper	Toowoomba
Beryl Green	Charters Towers
Ann Rutledge	Longreach
Julie Angus	Winton
Phillip Conti	Winton
Peter Person	Walkamin
Susan Sewter	Mornington Island
Joel Ah Kit	Mornington Island
Henry Callope	Normanton
Gladys Callope	Normanton
Ros Griffith	Mt Isa
Larry Morris	Mt Isa
Roanne Sanders	Mt Isa
Peter Gregory	Mt Isa
Gordon Burley	Mt Isa

Appendix 3: Teleconference Participants

Name	Location
Simon Bridge	Cairns
Debbie Lyn	Roma
Adrienne Hicks	Cairns
Danny Ruben	Bamaga
Beryl Spencer	Gympie
Mick Courtney	Quilpie
Lyn Noelene	Townsville
Stephen McDonald Michael Burg	Toowoomba
Faith Salter Donna Jodie	Mackay

Appendix 4: Workshop Evaluation Form

Centre for Rural and Remote Mental Health - Queensland Implementation Project

CONSUMER AND CARER WORK SHOP EVALUATION

We would appreciate your opinion of the workshop.

Are you a:

<input type="checkbox"/> Consumer	<input type="checkbox"/> Indigenous person
<input type="checkbox"/> Carer	<input type="checkbox"/> Non Indigenous person

Please circle the number closest to your opinion.

1 = strongly agree, 2 = agree, 3 = unsure, 4 = disagree, 5 = strongly disagree

The Workshop program was easy to understand.	1	2	3	4	5
The workshop was relevant to me.	1	2	3	4	5
I was able to talk about my views of informal care.	1	2	3	4	5
I was able to talk about my views of self care.	1	2	3	4	5
The workshop was well organised.	1	2	3	4	5

Comments and suggestions about the Workshop are welcome.

Would you please number the following issues (1 – 7) in order of their importance to you?

1 = Most Important 7 = Least Important

- Employment**
- Prejudice in the community about mental health problems**
- Mental Health Services**
- Respite support**
- Accommodation**
- Social Isolation**
- Access to general services and activities in the community**

THANK YOU FOR COMING TO THE WORKSHOP, SHARING YOUR EXPERIENCES AND COMPLETING THIS EVALUATION.