



Fetal & Infant Mortality Review (FIMR) Collaborative Innovation Network (COIN)

April 18, 2016 / April 19, 2016

AUDIO OPTIONS:

OPTION 1: Accept audio option via computer

OPTION 2: Dial in separately:

Toll: 1-203-607-0666; Toll-free: 877-951-7311

Participant passcode: 7159944

Webinar link: <https://hrsa.connectsolutions.com/pcoiinls/>



General Housekeeping



Please note the following:

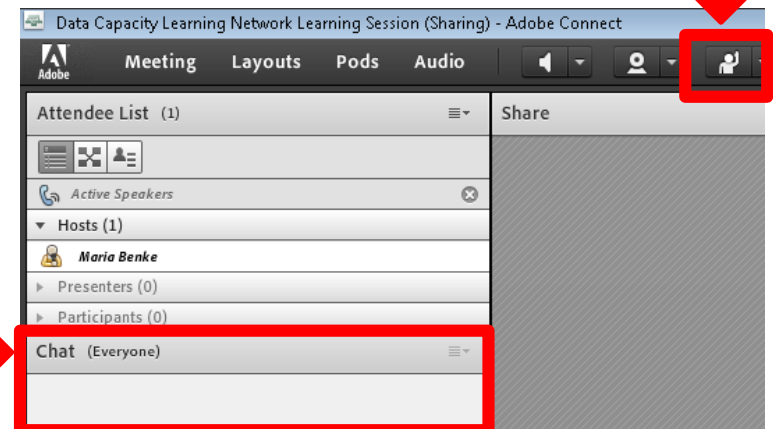


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- Participants are encouraged to share and ask questions throughout the session.
 - All participants will be muted while during presentations.
 - Use the “Raise Hand” function to be unmuted OR comment/ask questions using the chatbox.
- Please do not place this call on hold, we will be able to hear your music.
- Self monitor breaks and distractions



Functions:

- Raise your hand
- Use the chat box





Agenda



Fetal and Infant Mortality and Review (FIMR) Collaborative Innovation Network (COIN)
Agenda – April 2017

Welcome & Introductions

Presentation:

Grief, Loss, & Compassion Fatigue

Resources & Updates

Next Steps & Adjourn



Objectives



CONNECT

- Convene jurisdiction partners who may work together as a FIMR Case Review Team and/or Community Action Team

SHARE & LEARN

- Discuss issues related to grief and loss after a fetal or infant loss, for families and workers
- Ways to cope with grief and loss/vicarious trauma
- Resources to support your team

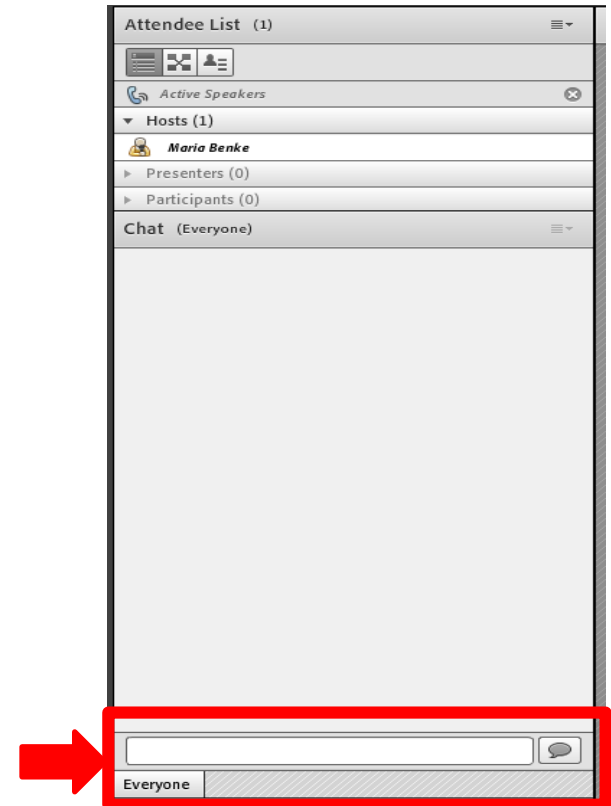
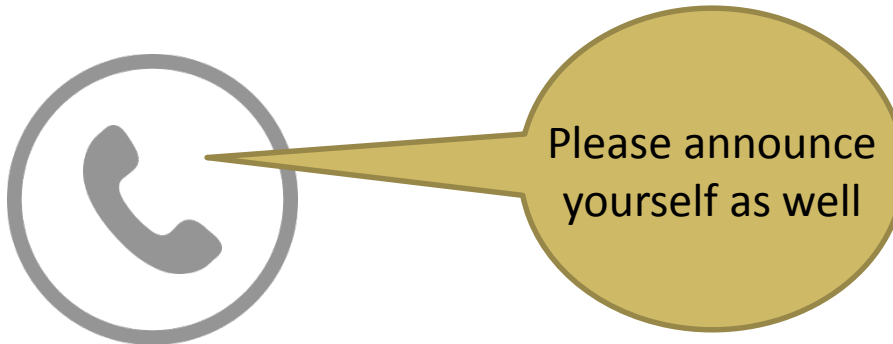


Introductions



Use the chat box to type in your:

- Jurisdiction.
- Name(s).
- Role in relation to FIMR (e.g. CRT or CAT)





Opening



FIMR is an action-oriented community process.

It brings a multidisciplinary community team together to examine confidential, de-identified cases of infant death.

It is very stressful.





Nancy Maruyama, RN, BSN

Executive Director, SIDS Illinois, Inc.

IM CoIIN Safe Sleep Learning Network

GRIEF, LOSS, AND COMPASSION FATIGUE



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Caring for the Caregiver

Self Care and Coping

Nancy Maruyama, RN, BSN

SIDS of Illinois, Inc.

April 18, 2017

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Why “Caring for the Caregiver?”

The challenge is balancing the desire and need to help others while maintaining your physical, emotional and spiritual health.



“If I were doing well with my grief, I would be over in the corner, curled up in the fetal position crying, not standing here acting like no-one has died.”

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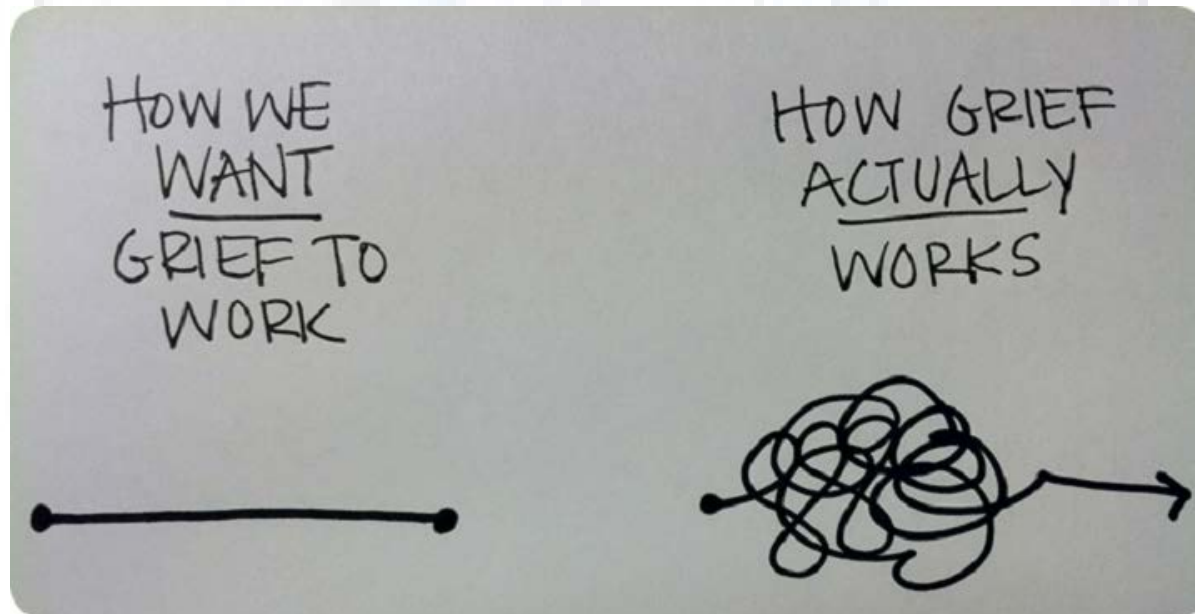
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Grief is a normal reaction to losing a loved one, but people mourn their loss in different ways.

Grief – inward feelings and thoughts about loss

Mourning – external expression of grief





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Grief Activity

- How have you experienced grief?
- How did you manage to get through it?
- When you are down, what helps to comfort you?
- What was your most profound loss?
- As a caregiver, what do you think is your greatest strength that can help a grieving person?
- What do you think is your greatest weakness that will NOT help a grieving person?

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Entering the Space of Another's Grief...

- requires a willingness and courage to enter the space of another person's pain
- no way to enter this space of pain and loss while remaining defended and protected against the emotional impact
- healthcare professionals can feel helpless, overwhelmed and defeated when working with bereaved parents



- as healthcare professionals, it is important to offer compassionate objectivity
- it can be difficult to avoid becoming personally absorbed into a family's grieving
- need to know own personal needs and limitations
- can be involved and concerned with family but remain separate from their grief
- make sure to take time away from doing bereavement work to deal with your own feelings and rekindle your energies



The Sound of Silence...

People talking without speaking,
People hearing without listening,
People writing songs that voices
never share,
No one dared disturb the sound
of silence.



A Mature Attitude Toward Death is Based on 3 Facts:

Death is universal

Death is inevitable and irreversible

Death is the physical cessation of life



“Courage is the mastery of fear, not the absence of fear.” Mark Twain

- courage – having the heart to take action despite fear
- acting on courage – nothing short of heroism
- working in crisis situations causes us to face our own grief
- it is important to recognize the manifestations of grief and to facilitate your own healing when a tragedy hits too close to home



What is Compassion Fatigue?

- Normal displays of chronic stress resulting from all of the care giving done
- Can have a negative effect on your life can lead to positive change and resiliency
- Symptoms Include:
 - Bottled up emotions
 - Isolation from others
 - Excessive complaining from and about others
 - Substance abuse
 - Poor self care
 - Mentally & physically exhausted

www.compassionfatigue.org



PTSD

- “Stress is a hazard of the workplace.”
- Unresolved grief and stress can affect career, self esteem, family life and relationships with superiors or co-workers
- If left untreated, chronic or long term stress can lead to PTSD

OSHA

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Know Yourself

- Recognize – do not ignore – feelings
- What do you think some physical symptoms might be?
- How can you resolve some of the physical symptoms?


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"Grief is **NOT** a disorder,
a disease or sign of weakness.

It is an emotional, physical and spiritual
necessity, the price you pay
for love. 

The only cure for grief is to
grieve" -- Earl Grollman

 unspokengrief.com

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Know Your Limitations

- Consider a 2 person team – it helps to have someone there to “tag team”
- Give yourself permission to take a time out – excuse yourself for a few minutes to gather your thoughts.
- Ask for help. It is not a sign of weakness to reach out for help.
- Realize you are not perfect and that you cannot always “fix” everything.
- Stick with a time limit; 1 hour at the most.
- Express your needs verbally
- Clarify your boundaries – what does and does not work for you

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Seeking Closure

- What does closure mean to you?
- Identify your emotions.
- Review details of incident
- Follow up with family.
- Share your feelings with co-workers
- Write about how you feel.



Be Proud of the Good

- Identify the “rights” you have done for the family
- Reflect on how much you have learned
- Be proud of your agency’s standard of care
- Focus on the compassion you offered and the impact it will have on the family



“There is within each of us a potential for goodness beyond our imagining; for giving which seeks no reward; for listening without judgment; for loving unconditionally.”

Elisabeth Kubler-Ross, MD

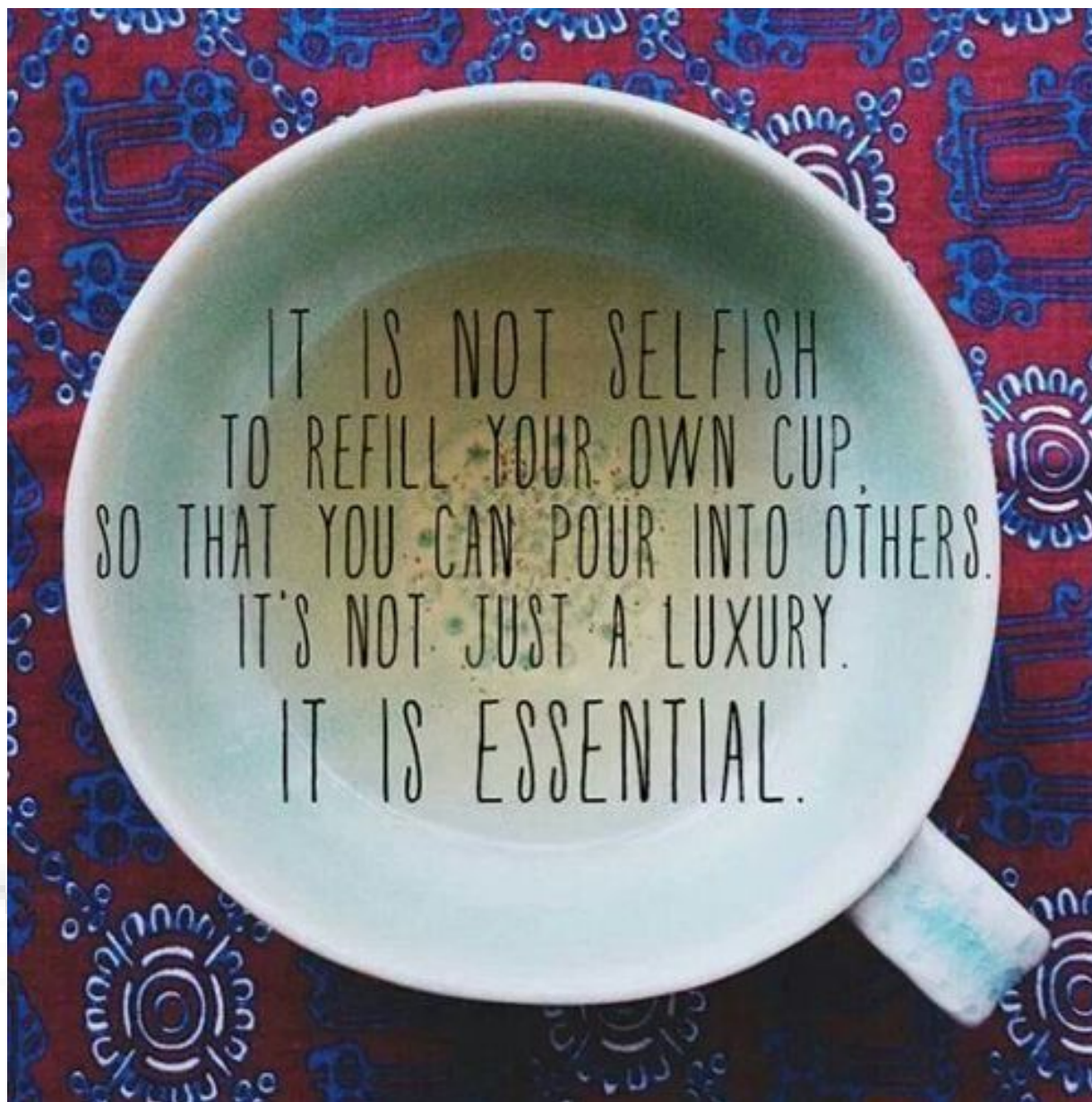


What can we do for
ourselves?

How can we re-fill our cup?

What happens if we don't
re-fill our cup?





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Some Strategies to Reduce Stress

Meditate. A few minutes of practice per day can help ease anxiety. ...

Breathe Deeply. Take a 5-minute break and focus on your breathing. ...

Be Present. Slow down. ...

Reach Out. ...

Tune In to Your Body.

Take a break.

Take care of yourself. Eat healthy, well-balanced meals, drink plenty of water...

Talk to others. Share your problems and how you are feeling and coping with a parent, friend, counselor, doctor, or pastor.

Avoid drugs and alcohol. Drugs and alcohol may seem to help with the stress...



Brendan N. Maruyama

June 1, 1985 – October 18, 1985



“We are a family of
five,
that has learned
to live as
a family of four.”

Nancy Maruyama

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**To contact the SIDS of Illinois, Inc.
directly, please call toll free
1-800-432-SIDS**

Sudden Infant Death Services
of Illinois, Inc
6010 State Route 53 Suite A
Lisle, IL 60532
630-541-3901 office
630-541-8246 fax
www.sidsillinois.org



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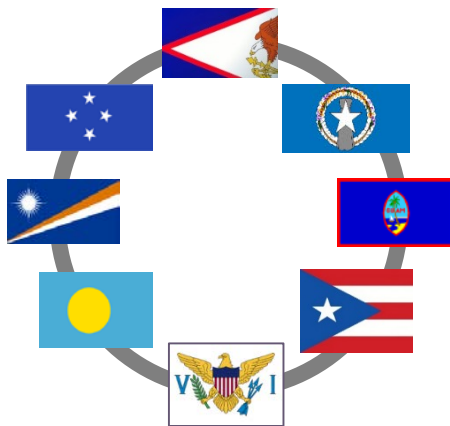




Group Discussion



- What support is available in your jurisdictions related to grief and loss?
- How can members of your FIMR team support each other?
- What do/can your Community Action Teams do to support grief and loss in your jurisdictions?





Jurisdiction Teams



What you can do as a team:

- Practice coping strategies together.
- Establish support groups for families and/or workers.
- Find ways to honor the children who passed.
- *Others?*



Grief & Loss Resources



Bereavement Resources

Professional Articles

- Guidelines for healthcare professionals supporting families experiencing a perinatal loss <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC280762/>
- Complicated grief after perinatal loss <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3384447/>
- Caring for Families Coping With Perinatal Loss *Journal of Obstetric, Gynecologic, & Neonatal Nursing*; [Volume 37, Issue 6](#), pages 631-639, November/December 2008
- Limbo, R., & Kober, R. (2010). The tie that binds: Relationships in perinatal bereavement. *Maternal Child Nursing*, 35(6) 316-321.

Websites

- 1st Candle: in 2017 merged 1st SIDS Foundation and 1st Candle, committed to the elimination of Sudden Infant Death Syndrome, Sudden Unexpected Infant Death and preventable Stillbirths through education and research while providing support for grieving families who have suffered a loss. <http://1stcandle.org/>
- Compassionate Friends: support to grieving families related to child loss <http://www.compassionatefriends.org/>
- March of Dimes: resources for families and professionals on miscarriage, stillbirth, premature birth and infant death. <http://www.marchofdimes.org/complications/loss-and-grief.aspx>
- Pregnancy Loss and Infant Death Alliance (PLIDA): supports healthcare practitioners and parent advocates in their efforts to improve care for families who experience the death of a baby during pregnancy, birth, or infancy. <http://www.plida.org/>
- Miss Foundation: Counseling, advocacy, research and education services to families experiencing the death of a child <http://missfoundation.org/>
- Star Legacy Foundation: awareness, research, education, advocacy and family support regarding stillbirth, pregnancy loss, and neonatal death.

BEREAVEMENT COUNSELING FOR SUDDEN INFANT DEATH SYNDROME (SIDS) AND INFANT MORTALITY: CORE COMPETENCIES FOR THE HEALTH CARE PROFESSIONAL

Association of SIDS and Infant Mortality Programs
Continuously bringing you the latest on grief counseling, education, advocacy and research

Shared with the FIMR COIN:
List of bereavement resources & bereavement counseling for SIDS & IM

NFIMR
July 2007

BULLETIN
A Publication of the National Fetal-Infant Mortality Review Program

When an Infant Dies: Cross Cultural Expressions of Grief and Loss III.
Jodi Shaffer, RN, PhD

INTRODUCTION

This bulletin summarizes a panel presentation from the National Fetal and Infant Mortality Review Program Fifth National Conference, held August 12-14, 2004 in Washington, D.C. It explores the cultural traditions of Hispanic, African American, and Jewish families grieving the loss of an infant. The Bulletin is the third in a series focused on cross-cultural grief and loss. The introduction contains an updated review of the literature on grief and loss.

Readers are encouraged to review the two previous NFIMR bulletins, *Cross Cultural Expressions of Grief and Loss II: When an Infant Dies* (2003) addresses changing U.S. demographics and presents perspectives on loss during pregnancy and infancy from the African American, French and English Caribbean, Hispanic/Latino, Chinese, and Ojibwa cultures. *When an Infant Dies: Cross Cultural Expressions of Grief and Loss* (1999) provides insights on the customs and values affecting expressions of perinatal loss, Native American, African American, and Muslim populations. These documents can be accessed on line at www.fimr.org. Hard copies are available by writing to NFIMR at 409 12th Street SW, Washington, DC 20024.

It is evident that there are similarities and differences in the grieving process for families from different ethnic and cultural backgrounds. There are significant variations even within a particular population. Broadly defined groups such as Arab-American and African Americans encompass people of considerable diversity in nationality, religion, history, culture, and politics. Members of more narrowly defined groups such as the Hispanic and Jews still differ in important ways such as level of assimilation into the majority culture, religious convictions, and national heritage. Service providers are challenged to assimilate both the cultural and personal aspects of each family to understand their unique experience. There is no magic formula or 'cookbook' for working successfully with families of different cultures. The best approach is perhaps the simplest—all family members, "How can I help you?" and then listen carefully to their answers. Each bereaved mother, father, and family member may have different needs. Learning how these needs may be shaped by cultural traditions and values can help providers avoid being judgmental and determine how to provide the most effective, respectful support in each case.

Effective support of families who have suffered a fetal or infant loss begins with a self-assessment of one's own cultural background as well as one's knowledge of and attitudes toward other cultures. It is important to note that every person views different cultures differently. There are significant variations even within a particular population. Broadly defined groups such as Arab-American and African Americans encompass people of considerable diversity in nationality, religion, history, culture, and politics. Members of more narrowly defined groups such as the Hispanic and Jews still differ in important ways such as level of assimilation into the majority culture, religious convictions, and national heritage. Service providers are challenged to assimilate both the cultural and personal aspects of each family to understand their unique experience. There is no magic formula or 'cookbook' for working successfully with families of different cultures. The best approach is perhaps the simplest—all family members, "How can I help you?" and then listen carefully to their answers. Each bereaved mother, father, and family member may have different needs. Learning how these needs may be shaped by cultural traditions and values can help providers avoid being judgmental and determine how to provide the most effective, respectful support in each case.

Effective support of families who have suffered a fetal or infant loss begins with a self-assessment of one's own cultural background as well as one's knowledge of and attitudes toward other cultures. It is important to note that every person views different cultures differently.

AIP This third Bulletin summarizes a panel presentation at the National Fetal and Infant Mortality Review Program National Conference August 12-14, 2004 in Washington, DC. The panel and this Bulletin were produced in partnership with the Association of SIDS and Infant Mortality Programs. NFIMR gratefully acknowledges their contribution to the development of this topic.

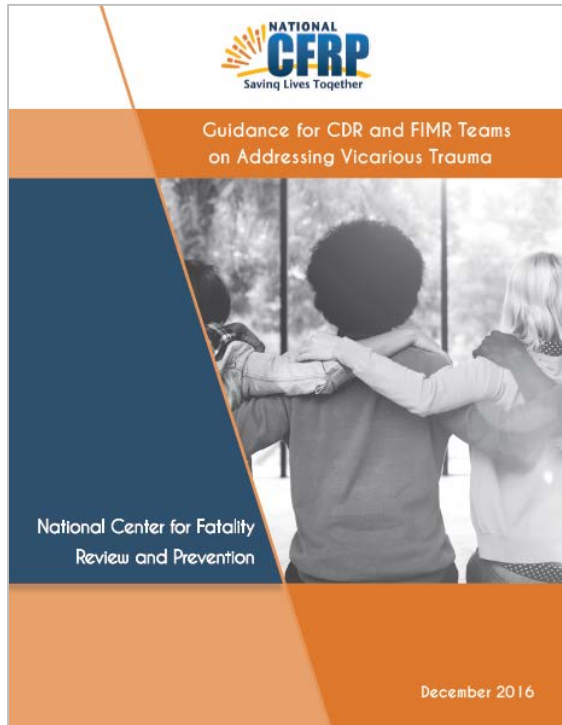
Other resources:
National FIMR Program
<http://www.nfimr.org/>



Vicarious Trauma Toolkit



Center for Fatality Review and Prevention
<https://www.childdeathreview.org/>



Vicarious Trauma Toolkit

Articles

1. Excerpts from *Caring for the Caregiver: Avoiding and Treating Vicarious Traumatization*. 2003. From *Sexual Assault, Victimization Across the Lifespan*, pp 6-14. Excerpt discusses briefly the protective factors that help alleviate or protect against the development of VT, but spends more time on features of organizations that actually contribute to VT (he calls it a "sick system"), then focuses on what can be done by the caregiver (the one who experiences the VT), and ends with a conclusion recommending "organizational universal precautions" to protect against VT and provide appropriate support when it happens.
2. *Vicarious Traumatization: A Concept Analysis*. 2011. *Journal of Forensic Nursing*. 2011. Pamela Tabor. Discusses VT, "repetitive invasion of another's trauma," discusses and distinguishes among the various terms similar to VT, and concludes with discussions of prevention of VT and interventions to take when someone suffers from VT.

Self-inventory checklists

3. *Professional Quality of Life Scale (PROQOL)*. 3-page worksheet, begins with questions, and then gives score based on questions with respect to compassion satisfaction, burnout, and secondary traumatic stress.
4. *Intervening to improve compassion fatigue resiliency in nurse residents*. 2016. K. Flarity, J. Jones, P. Reckard. *Journal of Nurse Education and Practice*. 6:12.

PowerPoint presentations

5. *Reducing Vicarious Trauma of Child Death Review Team Members and Staff*, October 2015 National Center presentation
6. *Secondary Trauma, Self Care, and Application to Child Fatality Review*. Amy Goldberg, MD, Brown University, and Leigh Reppas, LICSW, Rhode Island Youth Suicide Prevention Program. Short PowerPoint that discusses secondary trauma, warning signs, recognition barriers, trauma stewardship, person and team self-care recommendations, and examples of activities.
7. *Self-care: Coping with client deaths*. 2015. Abby Collier, Wisconsin CDR/FIMR and Children's Health Alliance of Wisconsin.
8. *Vicarious Trauma and Posttraumatic Growth: Identification and Interventions* (for health care providers), Randy Chang, Psy.D. & April Rectanus, University of Maryland Care Clinic. Defines VT, then discusses risk factors, how VT might manifest itself in healthcare settings, vicarious posttraumatic growth, and talks about use of self-care plans to prevent/treat VT.
9. *Vicarious Trauma and Self Care for CDR Teams*, August 2013. National Center presentation given in Tennessee. Short PowerPoint about vicarious trauma and child death review teams: how to identify, prevent, and address it.
10. *Resiliency Techniques for Responding to Mass Tragedies, Communities Trauma, and Violence*. 2013. Siddharth Ashvin Shah, M.D., MPH. Discusses stress and using trauma-informed care to help a traumatized individual, and then switches to discussion of community trauma, an "event that causes terror and leads to substantial losses." The PP concludes with a role-playing exercise for caregivers of traumatized individuals.
11. *Mental Among: Mitigating the effects of vicarious trauma for law enforcement officers, first responders, and mental health personnel who respond to the trauma of others*. 2013. Siddharth Ashvin Shah, M.D., MPH, with Stress Inventory, Greenleaf Integrative Strategies; Resiliency in Work & Society Workshop presentation and activities. Topics are neurobiology of stress and trauma, debunking old myths about resiliency, providing updated approach to resiliency, a list of what resilient workforces avoid, plus exercises/activities about stress and resiliency.

Other resources

12. *Trauma Stewardship: An Everyday Guide to Caring for Self While Caring for Others*. 2007. Laura van Dernoot Lipsky. 2007.
13. *Concept Map of Vicarious Traumatization*, Pamela Tabor. Schematic of the factors of empathic engagement of victims of trauma that can lead to VT and a brief representation of services to address the VT.
14. Bibliography. *Victim Advocacy Training, Vicarious Trauma References*. 2014. National Children's Advocacy Center.

https://www.childdeathreview.org/tools_and_resources/vicarious-trauma-toolkit/



Resources (cont.)





UPDATES



Upcoming...



FIMR Skills-building session
HRSA/MCHB Title V TA Meeting
San Francisco, CA

JULY FIMR COIN (TBD):
Using the FIMR Process to
Review Zika Cases

May

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June

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1-1 TA/ Coaching as needed

FIMR COIN
Meeting



Updates & Alibis





Closing thoughts





Questions & Comments to:

Rosemary Fournier, NCFRP, rfournie@mphi.org

Christina Rattleff, AMCHP, crattleff@amchp.org

CDR Maria Benke, MCHB, mchenke@hrsa.gov