Person-Centered, Trauma-Informed Care for our Clients, our Agencies, and Ourselves

NJHSA Conference
April 30, 2018
Chicago, IL
The Administration for Community Living is:

• Administration on Aging (AoA)
• Administration on Disability (AoD)
• Administration for Intellectual and Developmental Disabilities (AIDD)
• The Independent Living Administration
• Paralysis Resource Center; Limb Loss Resource Center
• State Health Insurance Assistance Programs (SHIPs)
• National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR)
• Workforce Innovation and Opportunity Act programs (WIOA)
• Traumatic Brain Injury (TBI) Program

• ACL is charged with developing policies and improving supports for seniors and persons with disabilities of all ages.
ACL’s Authorizing Statutes & Programs

- Older Americans Act of 1965 (as amended)
- Public Health Service Act Programs
  - Section 398 – Alzheimer’s Disease Supportive Services Program (ADSSP)
  - Title XXIX – Lifespan Respite Care Program
- Health Insurance Portability and Accountability Act of 1996 (HIPAA) – Health Care Fraud and Abuse Control (HCFAC) funds
  - Senior Medicare Patrol
- Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act)
- Help America Vote Act (HAVA)
- Workforce Innovation and Opportunity Act of 2014 (WIOA)
  - Independent Living Services/Centers for Independent Living
  - Assistive Technology Act
  - National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR)
- Other Programs
  - State Health Insurance Assistance Program (SHIP)
  - Paralysis Resource Center
  - Limb Loss Resource Center
  - The Traumatic Brain Injury (TBI) Act
The OAA: Flexible Core Programs and Supports for Innovation

- **Title III – B, C, D & E: Health and Independence**
  - In-home and community services (III B – transportation, case management, etc.)
  - Congregate and Home Delivered Meals (III C1 & C2)
  - Health Promotion & Disease Prevention (III D)
  - Caregiver Support (III E)

- **Title IV – Activities for Health, Independence and Longevity**
  - New approaches, demonstrations, and TA (sec. 411)

- **Title VI – Programs and Services for American Indians, Alaska Natives & Native Hawaiian Elders**
  - Services are comparable to Title III

- **Title VII – Protection for Vulnerable Elders**
  - Long-Term Care Ombudsman
  - Prevention of Elder Abuse, Exploitation
  - Legal Services
Advancing PC/TI Supportive Services for Holocaust Survivors: ACL’s Vision

- 2013 White House Initiative focusing on health and social service needs of Holocaust survivors
- FY 2015 appropriations: $2.5 million “to help provide supportive services for aging Holocaust survivors living in the United States.”
- Develop programs and services grounded in the “trauma-informed” framework, while ensuring person-centered approaches are used.
  - ACL recognizes that traumatic events can impact anyone at anytime across the life course
  - Such events can influence one’s ability to accept and benefit from supportive services
  - An opportunity to advance Aging Network Capacity while having immediate impact
Advancing PC/TI Supportive Services for Holocaust Survivors: Program Priority Areas

• Advance Innovations in the delivery of supportive services to Holocaust survivors
  – Incorporate principals of PC/TI Care at the local level through sub-grants
  – Build cross-sector partnerships
  – Enhance capacities and foster innovations in service delivery

• Technical Assistance of a National Scope
  – Increase cross-collaboration
  – Develop communities of practice
  – Expand national recognition of the need for TI care
Builds on ACL/AoA’s 53-Year History...

- Of innovation in the field of aging
- Of testing new ways of meeting the needs of a growing and increasingly diverse population of older Americans
- Of paving the way for future providers of aging services to have access to cutting edge knowledge and practices
- Of improving programs and services in meaningful and lasting ways
- Of strengthening the responsiveness and capacity of the Aging Services Network
ACL Guidance: *Outreach and Service Provision to Holocaust Survivors*

- Mandated in the 2016 OAA Reauthorization
- Target audience: SUAs, AAAs, Aging Network Providers
- Frames the issue and population needs
- Focus on promising practices for outreach and service delivery: mental & physical health, nutrition, transportation, caregiver support, elder rights and legal services
- Can serve as a “conversation starter” or guide to collaborative efforts in the community
HHS Resource Guide to Trauma-Informed Human Services

- Launched in January, 2017 as a joint effort of ACF, SAMHSA, ACL, ASPE and ASH
- Concept papers: trauma, toxic stress, historic trauma, resilience, executive functioning, “compassion fatigue”
- Program/population-specific trauma resources
  - Older adults and persons with disabilities
  - Immigrant/refugee populations
  - Programs within religious communities
  - Victims of sexual abuse
  - Domestic/intimate partner violence programs
- Community spotlights/promising practices
Contact Me:

Greg Link, MA
Aging Services Program Specialist
ACL/AoA

For more information about ACL
U.S. Department of Health and Human Services, Administration for Community Living, Washington DC 20201
Phone: (202) 795-7386    Email: greg.link@acl.hhs.gov    Web: www.acl.gov
Implementing ACL’s Grant for Person-Centered, Trauma-Informed Care for Holocaust Survivors

Shelley Rood Wernick, Director
JFNA Center for Advancing Holocaust Survivor Care

NJHSA Annual Conference, April 30, 2018
What is Person-Centered, Trauma-Informed (PCTI)?

A **holistic** approach to service provision that promotes the dignity, strength, and **empowerment** of trauma victims by incorporating knowledge about the role of trauma in victims’ lives into agency programs, policies, and procedures.
Why Holocaust Survivors?

• Holocaust survivors have suffered trauma on many levels, and by definition they are all aging.
• Holocaust survivors’ trauma impacts them in different ways as they age
  – Physical
  – Psychological
Implementing ACL’s Grant

• Promote PCTI innovations for Holocaust survivors.

• Build national capacity to provide PCTI-based services to Holocaust survivors.

• Advance PCTI care in the broader Aging Services Network to serve older adults.
Multi-directional Collaboration

- National Technical Assistance
- Subgrantees
- Local Partnerships
56 Subgrants Develop >100 Models

JFNA Cohort Map

Alpha Cohort
All items

Bravo Cohort
All items

Charlie Cohort
All items

Here you can find a map of the JFNA cohort members by cohort.
Sharing Local Models

- Webinars
- Conferences
- Journals
- Cross Collaboration
Technical Assistance

- Monthly phone calls
- Site visits
- Evaluation Assistance
- Webinars
- Training Workshops
- Peer to peer learning
Method of Spreading PCTI

How do we bring PCTI programs to the Aging Services Network?

• Develop Models
  – By serving Holocaust Survivors

• Transfer Knowledge
  – Within same agency
  – Beyond
Spreading PCTI

Aging Services Network

Orgs serving Holocaust Survivors

JFNA Subgrantees
~70% to 90% of older adults have experienced at least one traumatic event (Kaiser et al.)
Examples of Older Adults with a History of Trauma

- Veterans
- Refugees
- Survivors of Domestic Violence
- Survivors of Sexual Abuse
- Survivors of Child Abuse
- Survivors of Elder Abuse
- Survivors of Human Trafficking
- LGBTI
- Holocaust Survivors
Bridging the Gap

Although trauma is pervasive, the fields are wide apart
How to Get Involved

- Webinars
- Submit proposal for RFP
- Website

Shelley Rood Wernick, Director, Center for Advancing Holocaust Survivor Care
The Jewish Federations of North America
HolocaustCenter@JewishFederations.org
What is Person-Centered Trauma Informed Care?

The Trauma-Informed Care paradigm helps to contextualize the lived experiences of individuals who have suffered significant trauma. It guides us both in our care of these individuals and our care of ourselves.
Trauma-informed Care (TIC) Principles

- Safety
- Trustworthiness through Transparency
- Choice, Voice and Empowerment
- Cultural, Historical and Gender Issues
- Resilience and Self Care

SAMHSA.GOV
SENSE OF COHERENCE (Antonovsky, 1979)

**COMPREHENSIBILITY**: the ability for people to understand what happens around them

**MANAGEABILITY**: to what extent they were able to manage the situation on their own or through significant others in their social network

**MEANINGFULNESS**: the ability to find meaning in the situation
Imagine...

- Write down three things that you would not want to live without.
- Exchange papers with someone close by.
  - Once you have someone else’s paper, arbitrarily cross out one item on the list.
  - Return the paper to its owner.
- What did you notice about your experience?

Trauma is often about loss.
JFS of Greater Kansas City:
Why has Trauma Informed Care work been such a natural fit?
Continuum of Trauma-Informed Approaches

Trauma Awareness: Understand the prevalence of trauma & its impact on holistic wellness.

Trauma Sensitive: Apply the core TIC principles and begin to embed the skills/concepts into daily practices.
Trauma Responsive: Adapt daily work environment and practices; while implementing procedures to support culture of support to staff and people serve.

Trauma Informed: Create organizational culture that embodies a resilience-focused mission; TI Principles are embedded within all layers of staff, environment, and polices.
Trauma Informed Care: The 4 Rs

- **Realizes** the widespread impact of trauma and understands potential paths for recovery
- **Recognizes** the signs and symptoms of trauma in clients, families, staff, and others involved with the system
- **Responds** by fully integrating knowledge about trauma into policies, procedures, and practices
- Seeks to actively resist re-traumatization
TIC Tool Kit

A range of practical skills that enable individuals and organizations to:

• more effectively deal with difficult situations
• build community of caring
• develop a deeper understanding of the effects of adversity and trauma
• build a common language
Create Safety

SAFETY = CONNECTION + BELONGING
Domains of Safety

- Physical: free from injury to the body; environment that evokes ease
- Moral: free from persecution for belief; diversity is celebrated
- Psychological: free from emotional distress, fear, anxiety, shame; compassion is a practice and mindfulness is promoted
- Social: free from bullying and peer isolation; connected to people/belonging
Trustworthiness

Transparency: make expectations clear from the very beginning
Support Choice, Voice & Empowerment

Provide as much choice as possible within limits provided.
Wellness Room - Before
Wellness Room - After
Wellness Room - After
Mindfulness: How PCTI Serves Clinicians, Clients and Agencies

Mindfulness is a state of active attention to the present moment.
How Mindfulness Helps

Without Mindfulness

Stimulus ➞ Reaction

With Mindfulness

Stimulus ➞ Mindfulness ➞ Response

Mindfulness creates space... replacing impulsive reactions with thoughtful responses.
Mindful Minute

- Check in - how are you feeling?
- Professional or personal goal for the day
- What are your resources - who can you ask for help?
- What’s one small way you’d like to incorporate one of our TIC Values to your work?

  - Safety
  - Trustworthiness through Transparency
  - Choice, Voice and Empowerment
  - Cultural Humility
  - Self Care and Resilience
Infusion and Impact of Person-Centered Trauma-Informed Care:

Programming & Clients

Yonit Hoffman, PhD
Director, Holocaust Community Services
CJE SeniorLife, Chicago, IL
Our Mission:
Dignity and Support for our Holocaust Survivors

Holocaust Community Services (HCS) helps to ensure that survivors can continue to live independently in the community and prevent premature institutionalization by providing concrete assistance, psychosocial support services & advocacy.

Holocaust Community Services (HCS) is a joint effort of CJE SeniorLife, Jewish Child & Family Services and Jewish Federation of Metropolitan Chicago, supported by grants from the Conference on Material Claims Against Germany, Inc., Jewish Federations of North America, and other foundations and donors.
Survivor Demographics

- There are approximately 500,000 Holocaust survivors worldwide, including over 200,000 in Israel.
- An estimated 109,000 to 130,000 Holocaust survivors in the U.S.
- About 25 percent of survivors live at or below the poverty line.
- The average age of a survivor is 79, with nearly a quarter who are 85 or older.
- Estimated 6,000 survivors in Chicago metropolitan area (based on 2010 survey, prior to expanded definition of Survivor eligibility)
Holocaust Community Services
Demographics

- HCS currently serves more than 1,100 survivors with monthly financial assistance, and over 1,800 in total with other programming, referrals, socialization and advocacy
- HCS quadrupled in clients served in past 4 years
- Rolling waitlist of 250-300+ survivors
- Age ranges 73-105 (average 85)
- 1/4 are under 80 years old
- About 94% of survivors served by HCS are from the FSU
Who is a Survivor?

Survivors of the Holocaust are defined as persons who lived in one of the countries that was occupied by, or under the influence of, the Nazi regime for various lengths of time between 1933 and 1945 (USHMM & Claims Conference).

Survivors may have experienced uprooting, deportation, labor and/or extermination camps. They may have lived in ghettos, in hiding, under false identities, or been perpetually on the run. Survivors’ families may have been killed in the “Holocaust by Bullets” (Desbois) -- mass shootings, such as “BabiY Yar” or thousands of other mass killings in the Former Soviet Union (FSU). Included in this group are those who were forced to flee (“evacuated”) because of persecution by/encroachment of the Nazis.
Holocaust Survivors from the Former Soviet Union: “Operation Exodus” . . . 25 years later

• Operation Exodus was an effort by the American Jewish community to raise $540 million to rescue Soviet Jews.

• Chicago efforts brought over 35,000 Soviet Jews from the FSU during “Operation Exodus” in the 1980s and 90s.

• The theme line “Never Again is Now” was used to tie the memory of the Holocaust to the hardships experienced by Soviet Jews.

• Many of those Soviet Jews who were born before 1945 were either directly persecuted by the Nazis or lost family, and, today, are recognized as Survivors of the Holocaust.

From By Design partners website:
PCTI Information Gathering with Survivors

Ways to identify a Holocaust Survivor & sensitively gather information

- It is often difficult to obtain information from Holocaust Survivors about their past. They may not wish to revisit and disclose details about their past, may be distrustful of intentions, or there may be language barriers.

- Asking simple questions can help identify a Survivor without directly asking: place of birth, date of birth, date of immigration to the United States, religion and languages spoken.

- Indications that a person is a Survivor may include heavily accented English, reverting to first language, lack of family members of same generational age, phrases such as “child of the war” (FSU), or a number tattoo on the arm (only two Polish concentration camps used those).

- Many forms of persecution are not the “iconic” ones that we are most familiar with. Believe and validate the experience and identification as a survivor.

- Once identified as a Holocaust Survivor, it is imperative that providers explain how the patient’s personal information will be used. Refusal to share any personal, financial or clinical information may be based on deep mistrust towards anyone who is not immediate family.
The Survivors
Each person who survived is unique

Different experiences before World War II

- Raised in different countries and cultures across Europe, North Africa, former Soviet Union, with different levels of religious observance and speaking different languages.
- Some lived in urban centers, others came from rural settings.
- Some completed high school or beyond; others were too young for school or were forced to leave school by the Nazis.

Different experiences during the War years

- Ghettos or forced-labor camps.
- Concentration Camps, extermination camps and death marches.
- Evacuations and fleeing.
- Loss of homes and all possessions.
- Hiding in the forests, in attics or closets or haystacks, or living under false identity for weeks, months or even years.
- Orphanages & convents
- Partisans & resistance
- Fighting on the Front
The Survivors
Each person who survived is unique

Different experiences after the War

- Many of those who survived came to the United States as young adults soon after the War, and established professions and families.

- Those from the FSU were older when they arrived, had more difficult adaptation; lost professional identities, had significant language barriers; had decades of Soviet regime experiences, poor health care, ongoing antisemitism, and immigration issues.

- Some had/have family resources and social support, many do not or have lost connections.

- Some shared their experiences, some did not.
The Survivors: Shared experiences of trauma - **External**

- Threat of death and injury
- Exposure to extreme violence
- Overwhelming sensory input, loud noises, bombardment; smells
- Exposure to unbearable weather
- Extreme deprivation -- thirst and hunger
- Prolonged physical, mental or medical abuse
- Lethal hard labor
- Extermination of families and communities
The Survivors: Shared outcomes & responses to trauma - Internal

- Prolonged state of helplessness and vigilance
- Dehumanizing treatment & deprivation of individuality
- Loss of identity/reference groups (family, friends, groups, occupations)
- Loss of normalcy - developmental phases, schooling, boundaries, normative relationships
- Degradation of self-esteem
- Unresolved bereavement and grief over loss of loved ones
- Guilt over surviving when others perished
- The stresses and stigmas of immigration
- Post-traumatic symptoms (acute, chronic, sub-clinical, late-onset)
- Vulnerability to new stressors, transitions, losses
Challenges Faced by Aging Survivors

Survivors face the same challenges that most elderly face — however with a layer of traumatic history that impacts each of these issues.

• Failing health & chronic conditions
• Decreased resources – poverty, hunger, cuts in benefits
• Loss (of friends and family, of independence, of lifestyle)
• Dementia, cognitive & memory declines
• Affective disorders – depression and anxiety
• Hospitalization or institutionalization – triggers

➢ PTSD (differential diagnosis with dementia)
➢ Delayed Onset PTSD
## Recognizing Trauma “Triggers”

<table>
<thead>
<tr>
<th>Lack of resources or safety</th>
<th>Food; access, “wasting”</th>
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<tbody>
<tr>
<td>Transitions, goodbyes, staff changes</td>
<td>Holidays, birthdays, anniversaries, ages &amp; stages</td>
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<tr>
<td>Triggering words</td>
<td>Lack of privacy/autonomy</td>
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<tr>
<td>Medical visits or procedures</td>
<td>Small spaces, crowds</td>
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<tr>
<td>Loud voices or foreign languages/accents</td>
<td>Lining up for services or treatment; “registering”</td>
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<tr>
<td>Darkness or bright lights, harsh or unpleasant smells</td>
<td>Patterns or colors (yellow, stripes)</td>
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<tr>
<td>Taking a shower/ bath</td>
<td>Loud or sudden noises</td>
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<td></td>
<td>Dogs and other animals</td>
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</tbody>
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Recognizing Indicators of re-traumatization:

Significant changes in behavior of an elderly person observed over a short period suggest that traumatic memories could have been reactivated. Signs include:

- Less able to trust and cooperate; may be more suspicious & may struggle to keep control.
- Mood changes: sudden or fluctuating affect; increased anxiety, irritability, anger/aggression, depression, seeming withdrawn, numb.
- Increased difficulty communicating. Can revert to first language and lose ability in English.
- New or increased physical complaints. It may be easier to seek medical than emotional help.
- Sleep difficulties: changes in sleep patterns, insomnia, and nightmares.
- Memory disturbances: flashbacks, distractibility, difficulty concentrating or completing tasks.
- May respond as if actually re-living the time of acute trauma and may not be reachable.
- Hyper-arousal and vigilance (as if re-experiencing an actual emergency).
- May begin to store foods or get rid of possessions as if preparing for emergency.
Empowerment:
Resilience & Strengths

“A strength-based paradigm . . . a resilience philosophy; people’s individual and collective behaviors, circumstances, and achievements that allow them to overcome adversity, or in the case of the Holocaust, the actions a person might have taken to survive and find meaning.”

(Greene and Graham, 2009)
Resilience & Protective Factors (pre-war, during war, post-war)

**Individual factors**
- Temperament & personality traits
- Genetic predispositions & physical characteristics
- Cognitive characteristics (e.g. intelligence, processing)
- Coping styles
- Individual skills

**Interpersonal/Relational factors**
- Familial warmth and stability
- Familial assets & resources
- Interpersonal relationships & affiliations

**Group/Collective factors**
- Social & community integration and support
- Cultural stability, values, beliefs, religious observance
Responding to trauma within PCTI service provision:

- **Concrete Services - Financial Assistance** (needs-based income & assets):
  - Food
  - Personal Care & Housekeeping
  - Medication
  - Transportation

- **Emergency Financial Assistance**: (needs-based income & assets): Urgent one-time needs (e.g. medical services or equipment, home repairs, utilities, funeral expenses, dental, etc.)

- **Case Management** (in partnership with JCFS)

- **Screening, Assessment & Resource Linkage** (in partnership with CJE SeniorLife and community agencies, such as local food pantries and other Jewish services)

- **Reparations/Restitution Assistance** (partner with HIAS Chicago, use of reparations expertise – e.g. Marks Law Firm, and pro bono legal services – e.g. Beit Tzedek)
HCS Services & Programs (continued)

- Counseling
- Support Groups (currently 7: 1 in English, 5 in Russian, plus a 2G group)
- Café Europa & Socialization Programs (4 large events 150-350 attendees, 12-15 smaller events)
- Community Education for Clients (e.g. Computer, Health, Mindfulness & Healing Arts, Legal Assistance)
- Recognition of Life Events (Birthdays, Losses)
- Intergenerational Programming (BBYO, Jewish schools, universities Hillel/ASB)
- Trainings & Case Consultation for Professionals – Trauma-informed Care & Cultural Competency (e.g. In-Home Caregivers, Hospice, Assisted Living and Skilled Nursing facilities, national conference presentations)
JFNA Grant: Person-Centered Trauma-Informed Outreach

- Trauma-informed
- Culturally-informed
- Addresses concrete needs/safety
- Addresses Isolation
- Empowerment
- Enhancing self-care & Independent living
- Intergenerational Programming

- PCTI In-Home Counseling & Case Management
- Computer Classes & Companions
- Empowering English Classes
- Healing Arts Classes
- Community Wellness Classes

CJE SeniorLife
Jewish values for positive aging
## PCTI In-Home Counseling with Survivors

### Challenges

- Hard to engage & work with Russian-speaking survivors in counseling even if they are struggling with losses, depression, and difficult health issues - survivor mentality (distrust, independence, pride, etc.)
- Cultural & Generational barriers: lack of experience with and understanding of traditional mental health services

### Strategies

- **PCTI practices:** safety first -- start with the services that the client requests, such as concrete assistance, *clinical* case management; Maslow’s hierarchy
- Reach survivors where they feel safe
- Words matter: **cultural sensitivity**
- Focus on building **trust** in the relationship and first; through building rapport, and learning personal stories; addressing concrete needs
- **Transparency:** address issues of therapist differences (culture, age, religion, etc.); limitations of services, common perceptions and misperceptions
- **Voice & Resilience:** ask about profession; use of literature or arts, client input
Giving Voice

Listen and learn

- Offer opportunity to tell their story *if they want to*, at their own pace
- Photos and memorabilia are a way to tell what words can’t
- Offer empathic listening to their stories - and respect the silences about these events
- Understand the client’s life prior to the Holocaust
- Focus on resilience and coping and how they still use these strengths
- Offer opportunity to “bear witness” (e.g. writing story or giving testimony to trained interviewers)
Chanukah Café Europa & USHMM Luncheon

CJE SeniorLife
Jewish values for positive aging
Summary of PCTI strategies in Working with Survivors

- Give the survivor as much control and choice as possible
- Respect & understand boundaries
- Assist others on the care team in understanding the client’s needs and advocate for creative care planning to reduce reactions to triggers
- If you observe a strong or unusual behavior, stop and consider whether something might be triggering a painful memory.
- Reframe “negative” behaviors as coping skills that helped them survive before and/or might be needed to control what is happening now.
- Help survivors and families to re-frame “fight for survival” to a “fight for comfort”

- Important to recognize there may be no “fix”
- Simply listen to the survivor and family and be there
- Be aware of your own feelings and responses & practice self-care
- Use team and supervisory support - talk with colleagues and supervisors to discuss emotions and challenges
Questions / Comments?

Greg Link  
Director of the Office of Supportive and Caregiver Services  
US Administration on Community Living  
Greg.link@acl.hhs.gov

Shelley Rood Wernick, MBA  
Director, Center for Advancing Holocaust Survivor Care  
Jewish Federations of North America  
Shelley.Wernick@jewishfederations.org

Laura Gilman, LCSW  
Care Management Team Manager  
Jewish Family services of Greater Kansas City  
LGILMAN@JFSKC.ORG

Yonit Hoffman, PhD  
Director, Holocaust Community Services  
yonit.hoffman@cje.net