

Ryan-White Carry-Forward Funds Long-Term Survivor Support Pilot Year 2: 2014-15

Alyssa Nickell, Ph.D.

Shanti Project
Director, Research and Program Development

Mike Hickey, LMSW

Shanti Project
Deputy Executive Director

Long-Term Survivor Support Pilot

Group-Level Programming:

 responds to the needs of LTS who are 50+

Need: Psychosocial Support

	Age ≥ 50 years (N=8,650)		Age < 50 years (N=7,251)	
	Number	<u>(%)</u>	Number	(%)
Gender				
Male	8,058	(93)	6,585	(91)
Female	465	(5)	441	(6)
Transgender	127	(2)	225	(3)
Race/Ethnicity				
White	5,928	(68)	3,832	(53)
African American	1,181	(14)	857	(12)
Latino	1,092	(13)	1,703	(24)
Asian/Pacific Islander	306	(4)	588	(8)
Native American	35	(<1)	55	(1)
Other/Unknown	108	(1)	216	(3)

- Reduction of social isolation among long-term survivors
 - Peer support
 - Activities that engage, educate and empower
- Increased access to clinical and non-clinical mental health services
 - Peer support
 - Health self-management counseling
 - Traditional (behavioral and narrative) and complementary therapies

Multi-year Pilot Collaboration

Year 1: Exploring and testing options

- Staffing
 - 2 consultants
 - Shanti staff for management, graphics and evaluation
 - Volunteers
- Smorgasbord of modalities
 - Town halls
 - Monthly and weekly groups
 - Smattering of social activities
 - Weekend retreats

Year 2: Streamlining for sustainability

- Staffing
 - 1 manager of HIV/Aging special projects (primary liaison)
 - Additional Shanti staff for capacity building, graphics and evaluation
 - Volunteers
- Streamlined and targeted modalities
 - Town halls
 - Weekly groups
 - Social and educational activities integrated into existing Shanti programming



Pilot Collaboration: Yr 2

SUSTAINABILITY

Shanti staff support:

- Management and event planning
- Capacity building and group facilitation
- Evaluation tools
 - Survey development, administration and analysis

Analysis and integration of year 1 outcomes

Adjustment of groups based on ongoing community feedback and leadership capacity

- Consistent
- Diverse
- Flexible

Prioritization, development and implementation of group-level programming

Follow-up in regular check-ins and staff meetings

GROUPS

Town Halls (N=4)

Linkage to individual psychosocial support:

Care Navigation Volunteer Peer Support Peer Health Counseling

- Consistent
- Diverse
- Flexible
- Integrated
- Sustainable

WEEKLY

Coffee-Chat

Group Exercise (7-week series)
Planning Meetings (bi-monthly)

Targeted Shanti group-level programming "Special invitation to LTS"

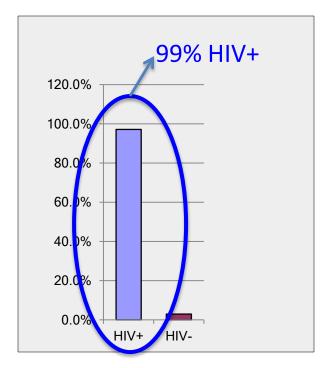
Survey Results: Quantitative

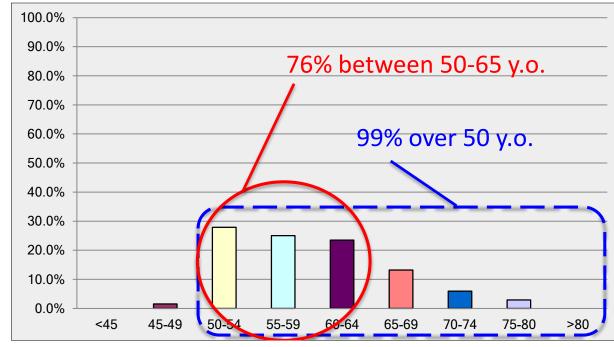
<u>Target audience:</u> Long-Term Survivors of the AIDS epidemic

- people who are HIV+
- over 50 years old

Target UDC: 50 – exceeded goal by 36% (N=68)

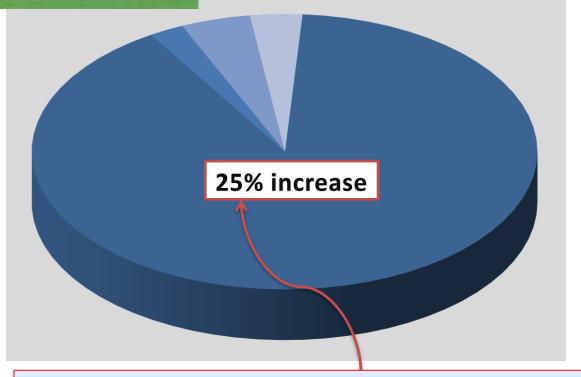
- Women 7%
- Non-white 18%





Survey Results: Quantitative





- 82% EMA
- 2% Sonoma/Sacrament o
- 3% Alameda
- 3% Other (Oregon, Palm Springs, unknown)

Streamlined programming and targeted outreach

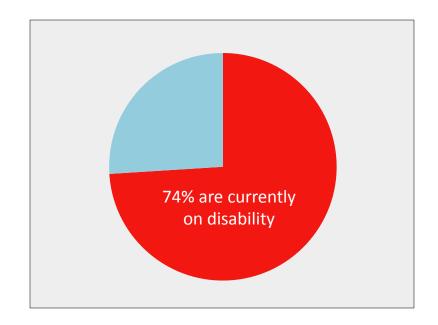
 75% know at least one LTS who needs support but is too shy or nervous to attend a group event

Survey Results: Quantitative

<u>Limited Income: on disability or employed less than full-time</u>

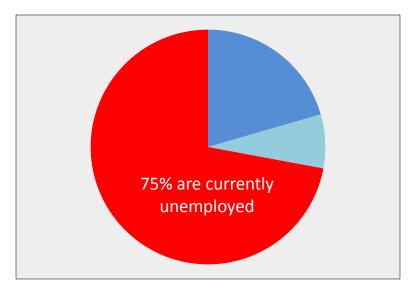
Disability

 74% of participants are currently on disability

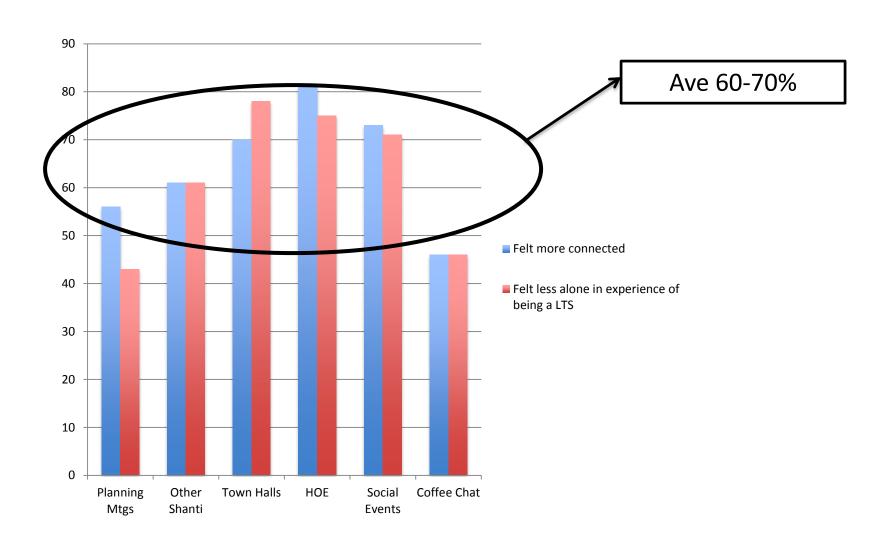


Employment

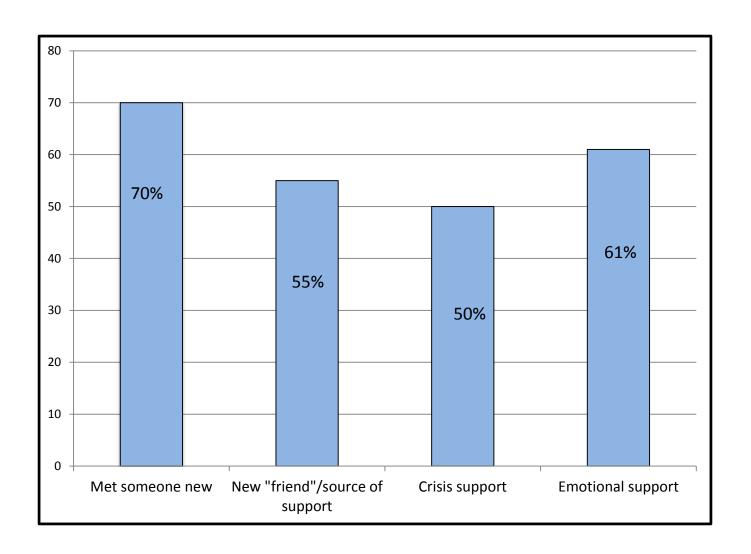
- o 75% are unemployed
- o 21% employed part-time
- 41% are interested in being employed
 - 90% interested in part time



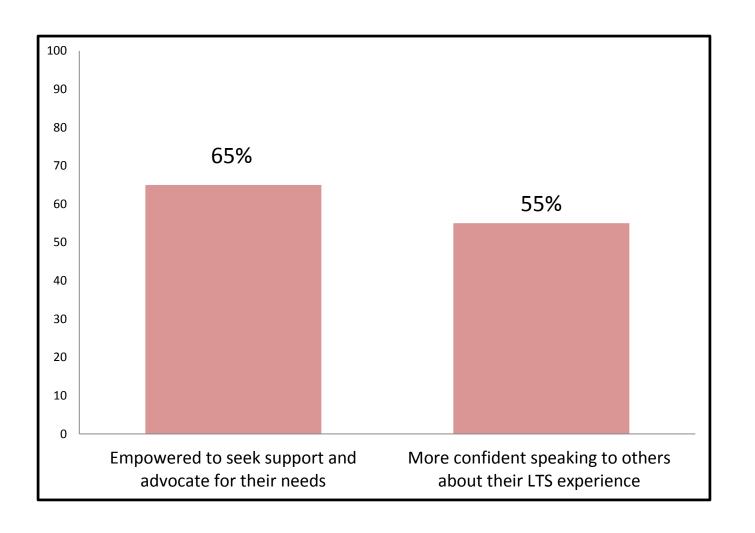
Survey Results: Increase connection and reduce isolation



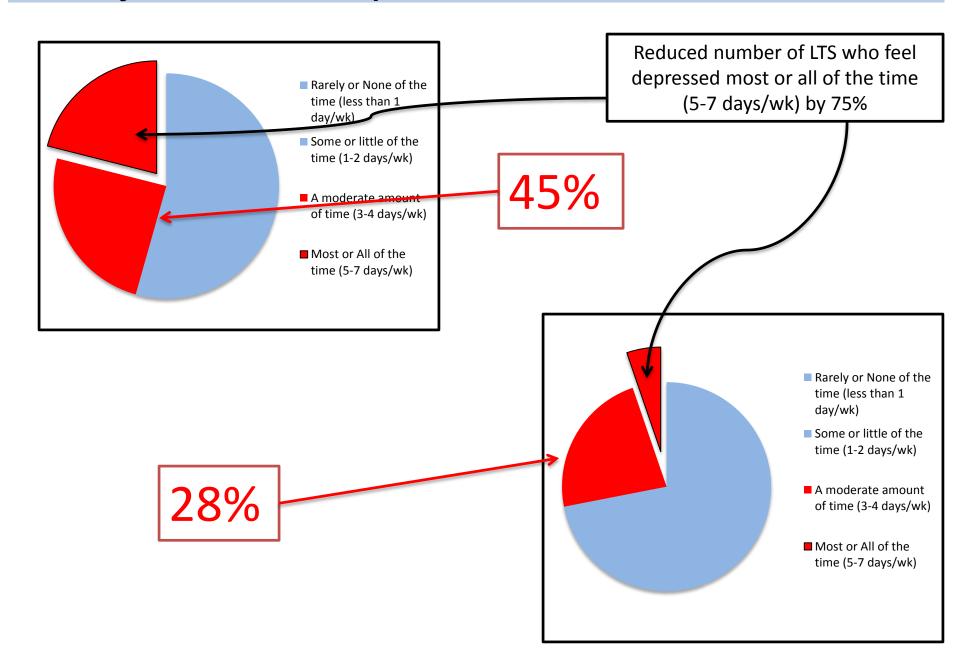
Survey Results: Increase connection and reduce isolation



Survey Results: Agency and Empowerment

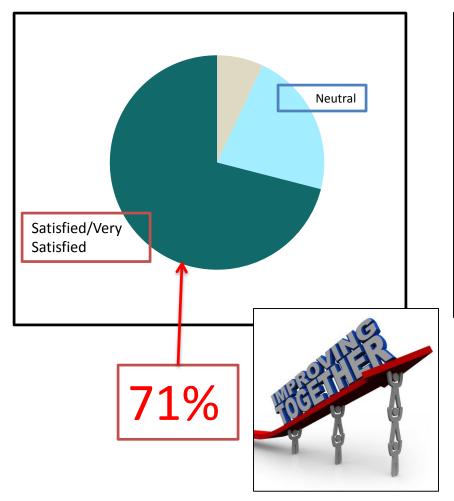


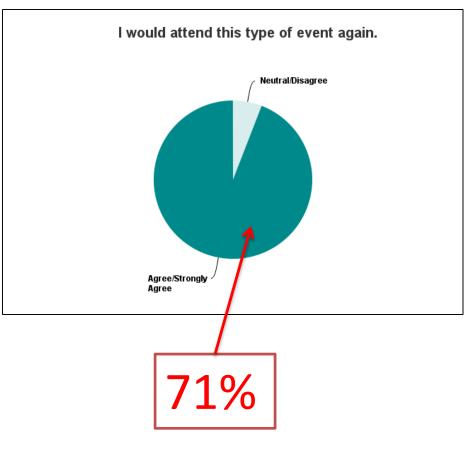
Survey Results: Depression



Survey Results: Survey Monkey

Overall satisfaction with group programming:





Survey Results: Qualitative Interviews

Goal:

< 10% of participants

Interview questions:

- Connection to LTS community
 - What does the LTS community mean to you?
- Shanti's role in providing LTS-specific programming
 - Are we currently serving the community?
 - What more/else can we do?
- PTSD and mental health needs
 - Symptoms?
 - What would you be willing to do to help yourself address these symptoms?
- SF response to LTS needs
 - Is SF doing enough?
 - What more/else can we do?



Survey Results: Successful groups

Groups that address symptoms of post-traumatic stress

Self-Awareness

I want to be open, honest and transparent about my personal reality in relationship to another.

To learn more about myself as I relate to others as a long-term survivor.

I want to understand how long-term positive people get trapped in a cycle of dependency and "victim identity" and how some support systems encourage such.

Trauma/Grief work + Positivity = Forgiveness and future-thinking

I have lost every man I ever loved; I carry a level of grief and trauma work, but am good and not letting it impact me. ... If you speak about your problems, you can serve others. I want to learn how to forgive and see the many differences between us all.



Survey Results: Successful groups

Groups that promote connection and wellness

Opportunities to Volunteer

I want an opportunity to give back to the community.

I love that we are starting to get together and realize that we have to be here for one another!

60% would volunteer to provide 1-on-1 peer support

Opportunities to Learn, Pursue Passions and Live with

Purpose

Opera, theatre, Alcatraz, Ballet, museums! I want to experience something new!



Opportunities to be seen and heard

We need to write a new narrative about long-term survival. We need to challenge the system. We need to stand up!



Survey Results: Successful groups

Groups that educate and increase access to vital resources

Opportunities to listen to experts

It would be great to have a list of resources, including mental health resources and decent legal resources and more trainings on how to be a better advocate for yourself.

Opportunities to gather in a safe and central locale
Coming to Shanti gets me out of the house
to a place where I always receive kindness
and a smile. The staff are skilled in problem
solving, non-judgmental and fun!

Opportunities to be role models

We need to create activities that helps new, young POZ people find their way – like a mentor program.



Moving Forward: Findings from Yrs 1 & 2

Grass-roots organizations play an important role

- Advocacy: public policy and protest
- Larger-scale educational events (Town Halls)
- Wide reach: outreach is not limited by restricted funding
- Learnings:
 - Consistent and varied group-level programming requires program development experience and infrastructure + human capital
 - Volunteers are amazing!
 - They need on-going coordination and support.

CBOs are responsible for ongoing programming

- Experience and infrastructure
 - Program development
 - Program implementation
 - Program evaluation
- Learnings:
 - Reliability, integrity and internal flexibility are KEY to community engagement
 - LTS are eager to participate in CBO programming
 - LTS understand the need for data
 - Intergenerational and interdisciplinary efforts are key to sustainability
 - Collaboration and coordination are key to comprehensive care

77% felt less alone in their LTS experience

VOLUNTEERS, WE THANK YOU!

During our last fiscal year, Shanti Peer Support Volunteers provided over 8,500 hours of service, valued at \$192,000!

Moving Forward: Targeted LTS Programming

- Varied, reliable, and measurable modalities
 - Consistent weekly groups
 - "Supportive" groups
 - Physical and mental health-enhancing activities
 - Traditional support group
 - Consistent monthly events
 - Social activities
 - Multi-day retreats to address grief/loss

Reliable and adaptive

- Seamless linkage to individualized psychosocial support services
 - Care Navigation
 - Volunteer Peer Support
 - Physical and Mental Health Services
 - Social Services
- New Collaborative Partnerships
 - Rafiki House
 - o Ward 86

Integrated and collaborative

NB: Can we expand LTS Programming to address needs of <u>all</u> long-term survivors?

Moving Forward: Future Funding

Sustainability

- Estimated costs:
 - \$40 K = 5 months (exploratory design and implementation)
 - \$100K = 6 months (leveraging strengths from yr 1)
 - \$100K = 6 months (targeted programming, leveraging strengths from yrs 1-2)
 - \$160K = 12 months (on-going implementation of sustainable programming)



Thank you!

- San Francisco Department of Public Health
- Let's Kick ASS
- Shanti Staff
 - Matt Sharp
 - Jack Bowman
 - Gregg Cassin
 - Matthew Simmons
- B.A.R.
- Participants in Shanti & LKA events, surveys and interviews

Contact Information



Alyssa Nickell, Ph.D. Shanti

Director of Research and Program Development 773-531-4898 anickell@shanti.org

Mike Hickey, LMSW Shanti

Deputy Executive Director 415-674-4716 mhickey@shanti.org