



Through Consumer Engagement

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Where It Began for Kim...



"F.C.T.A." ~ Family Caregiver Turned Advocate

Person-Directed Living: It's for EVERYONE

*"Without the human COMMUNITY,
one single human being cannot survive."*

~ Dalai Lama



consumer

[kuh n-soo-mer]

1. a person or thing that consumes.
2. a person or organization that uses a commodity or service.



*Have you been touched by the system of care
as a recipient, a family member, or as a friend...
OR all of the above?*

Where It Began for Laura...



Champions of Change:*



- Advocate:** works with people in authority who can change practices/policies
- Helper:** does everything in their power to make the situation better
- Organizer:** finds others to help create a passionate team--all about the numbers
- Rebel:** good at making a commotion; creating a degree of crisis

*Bill Moyer's Four Roles of Social Activism

This is a Revolution!



Revolutions are successful when they involve the stakeholders – Consumers!

What are the potential barriers for engaging consumers as advocates for changing the culture of care?



Let's Brainstorm in Small Groups!

Pair & Share Discussion

What are our own experiences as consumers of care services & support (as recipients or family members or friends)?

What did we take away from those experiences that inspired us to push for change?

Take 3 minutes each



What are the potential barriers for engaging consumers as advocates for changing the culture of care?



What Did You Come Up With?

When consumers make their preferences known and DEMAND change, it is more likely to happen!



We need to educate them, so they can be empowered Champions of Change!

ACROSS the Continuum



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VENUES of Care & Support



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Organizational Silos

Hospital World **“VS”** Nursing Home World **“VS”** HCBS World



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Constellation of Care



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We are all aging!

There is an ELDER growing inside each of us.



All of the silos are made up of **PEOPLE WHO NEED PEOPLE.**

HUMAN SILOS in Systems of Care



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How we *THINK* and *FEEL* about the culture of care and our role in it...

True mastery of culture change requires engaging all stakeholders in creating a life worth living.

Eden at Home ~ Eden in Community...

Applies Eden Alternative's Ten Principles and Domains of Well-Being to the needs of Elders, and their care partners, living in their own homes, wherever that home may be.

Encourages the creation of collaborative and supportive care partner teams that include the active participation of the Elder herself.

A person-directed model of care focused on quality of life for every member of the care partner team.

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Impact of Ageism & Ableism On Consumer Engagement



What We Saw Missing in 2003...



Traditional perspectives and attitudes positioned care as a one-way street, limiting quality of life/care.

We believed that redefining the caring relationship as a *two-way street* would enable all to thrive, *not just survive*.



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An Elder is...

Someone who, by virtue of life experience, is here to teach us how to live.



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Care is helping another to grow...



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The needs of caregivers and care receivers alike are part of an interdependent system called

CARE PARTNERSHIP



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What We Saw Missing in 2003...



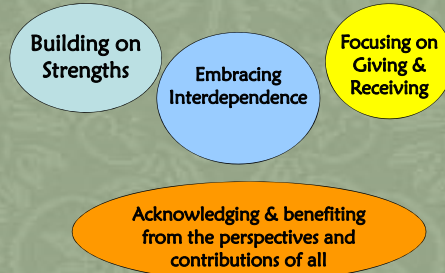
Existing consumer training typically focused solely on the experience of “caregivers”

We saw a powerful need to create a shared language about a new paradigm of caring between different stakeholders (Elders, care professionals, family members, neighbors, etc.)



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Learning Together... Creating Shared Learning Models...



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The Care Partner Team

- Person typically described as the Care Receiver
- Family Members
- Care professionals
- Friends
- Neighbors
- Volunteers



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Name one way you/your organization engaged consumers or the broader community in your culture change journey that was successful.

What were the strengths from that success that you can build on again?



Let's Share Our Stories in Small Groups!

What We Saw Missing in 2003...



Existing consumer training and supports typically siloed conversations and education about care

We saw an opportunity to offer a more integrated alternative by creating a learning experience that accommodates bringing different stakeholders together, to learn from each other, in a single class.



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Name one way you/your organization engaged consumers or the broader community in your culture change journey that was successful.

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Let's Hear What You Came Up With...

Pioneer Network Consumer Education Pilots

Funded by the Picker Institute

National pilot partners included:

AHCA, American College of Health Care Administrators, AMDA, Coalition of Geriatric Nursing Organizations, Leading Age, and The National Consumer Voice for Quality Long-Term Care



CULTURE CHANGE Network of Georgia



EA/National CMS Grant Project

Engaged family members, side-by-side with nursing home employees, to strengthen care partnerships and overall well-being on the team.

Integrated teams experienced dementia-specific version of Eden at Home Care Partner Workshop.

Positive reactions from both family and employees about the opportunity to work together.



Creating "EDEN" In Georgia



Dreams Come True Bringing Vision to Life...



~Challenges of getting people to see *Eden at Home* as vehicle for consolidating a person-directed, community-wide approach to care.

~Getting everyone on the same page.

~Finally... some solid examples emerge:

- Atlanta, GA
- Winston-Salem, NC



Senior Citizen Services of Metro Atlanta



Lutheran Towers HUD Housing in Atlanta



Winston-Salem Project

- Connecting these efforts to the larger *Age Friendly Community* and *Dementia Inclusive Forsythe County* initiatives
- Collaborating with Wake Forest University Baptist and Bowman Gray Medical School
- Integrating the EAH Care Partner Workshops into their “Money Follows the Person” program
- Fully integrating concepts into their adult day operations and practices



Winston-Salem Project



Initiator:
Senior Services, Inc.
Winston-Salem, NC

Offers 7 different categories of services including adult day, meals on wheels, home care support, etc.

The Role of Youth...

Got Youth?

Defeat
Ageism...



Building
Bridges

Bringing Youth and
Elders Together
Through Story and
Understanding

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Winston-Salem Project



- “Aging with Purpose” Initiative as launch pad
- Trainees chosen carefully across community services
- Engaged 6 other additional community partners
- 90+ employees across all these services have been introduced to Eden Alternative principles/concepts
- Offered EAH Care Partner Workshops to various faith-based communities
- Sharing person-directed care concepts with employees of Blue Cross/Blue Shield

The Role of Youth...

We need...

- Communities that view Elderhood as a valued phase of human development
- Well-integrated, supportive intergenerational communities



We need to keep in mind...

- We have an Eldercare workforce crisis.
- Person-directed care speaks to youth who seek meaningful work.
- We must take time to understand how to engage millennials, appreciate the strengths of this generation and leverage them.



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Name one thing you heard in this session that you wish to apply back in the greater community right away.

Do you have an idea of what that might look like?



Let's Share Our Stories in Small Groups!

“Change your thoughts and you change the world.”

~ Harold R. McAlindon



Together, we are stronger!

Questions? Comments?



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