

# *To Be Person- and Family-Centered*

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LTQA FOURTH ANNUAL CONFERENCE SEPT. 15, 2014

INTEGRATING LTSS FROM A PERSON'S PERSPECTIVE – ACROSS TIME AND SETTING

# *The Experience of Relying on Others - A Person-Centered View*

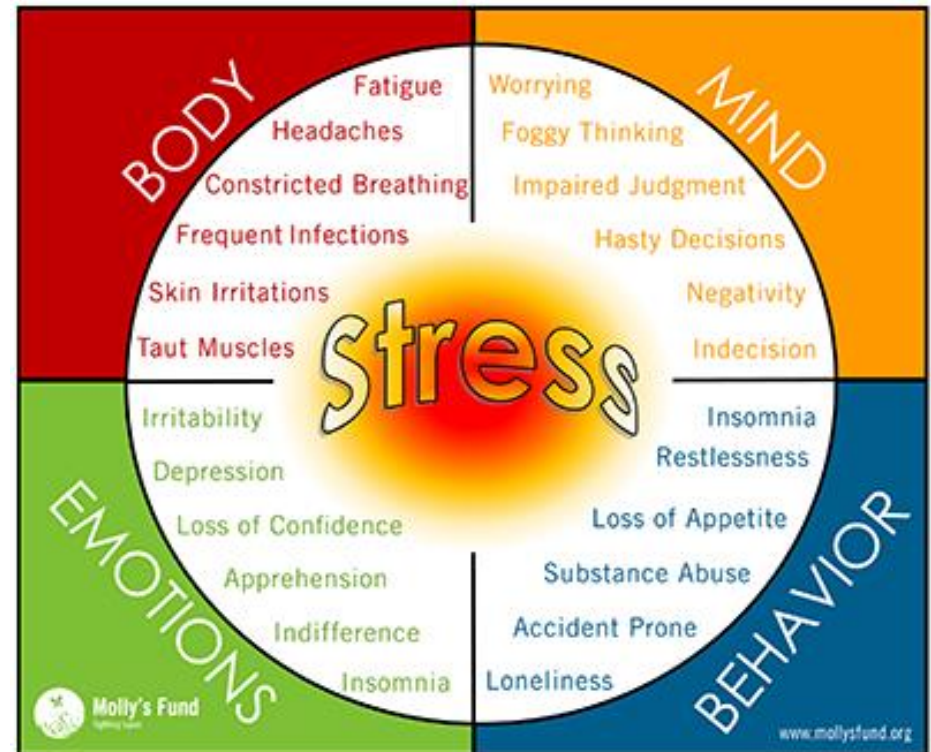
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- ❖ Needing help makes one feel **vulnerable, embarrassed, frightened, exposed, like a failure.**
- ❖ Feeling vulnerable, embarrassed, frightened, and exposed makes one feel **diminished.**
- ❖ Feeling diminished **undermines self-confidence and sense of self-worth.**
- ❖ Loosing confidence and a sense of self worth causes **depression and stress .**
- ❖ Depression and stress **compromise health and personal functioning.**

# *Depression and Stress Increase Cortisol*

## The presence of Cortisol

- Reduces bone formation
- Increases blood pressure
- Weakens the immune system
- Long-term exposure damages cells in the hippocampus causing impaired learning and inhibiting memory retrieval



*Donald M. Berwick, MD, MPP  
Yale Medical School Graduation Address  
May 24, 2010,*



*.....that small thing is what matters. I will tell you: it is all that matters. All that matters is the person. The person. The individual. The patient. The poet. The lover. The adventurer. The frightened soul. The wondering mind. The learned mind. The Husband. The Wife. The Son. The Daughter. **In the moment.***

- *The 90-year-old grandmother, over whom you tower;*
- *The professor in the MRI machine who has been told to lie still, but who desperately needs to urinate and is ashamed;*
- *The man who would prefer to know and as the man who would prefer not to know;*
- *The woman who would prefer to sit;*
- *The woman who would prefer to stand; as the man who wants you to call him, “Bill,” and as the man who prefers to be called, “Dr. Gruzenski.*

# *Helen*

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- ❖ 93
- ❖ Worked in the USO in Germany
- ❖ Lives and manages her affairs alone
- ❖ Studied at Julliard
- ❖ University Professor



# *Why it is so hard to be person-centered?*

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## **It is inconvenient**

- It takes time – often more than we think we have
- People chose priorities that we don't agree with even when we “know best”
- We might not make your deadlines
- The person doesn't want to follow our clinical or therapy protocols
- People won't fit within our schedule
- We can't use platitudes when we are communicating: we have learned to objectify people so that we can treat them without becoming emotionally exhausted – but we must be authentic.

**It's hard.....**every person that interacts with the person must consistently listen, focus on how the person and feels “treat” them like a customer.

# *Being Person-Centered Requires a Review of Every Process You Engage In*

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- ✓ Intake and Assessment – the 1<sup>st</sup> conversation
- ✓ Planning – the 2<sup>nd</sup> conversation
- ✓ Service delivery – the 3<sup>rd</sup> conversation
- ✓ Documentation that is easy, not intrusive and transparent to the person
- ✓ Payment and reimbursement rules
- ✓ Performance measurement – the 4<sup>th</sup> conversation

# *Intake and Assessment – the First Conversation*

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We ask intimate questions.

We ask about what is wrong, what the person can't do and need help with.

We ask other people around them to answer for them.

We ask the same questions over and over.

We don't ask the most important questions:

- Who are you?
- What is important to the you?
- What do you need to have a good day?
- What makes you happy?

We are often just collecting data whether it's important or not.



# Assessment: The Risk of PTSD

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***Jamie is my son. He is 22 years old.***

The Penn State Starter

*Michael Berube, Edwin Erle Sparks professor of Literature and director of Penn State's Institute of Arts and Humanities. Reprinted with permission from Al-Jazeera America*

It took about 45 minutes; I talked Jamie through it, and answered most of the questions for him (as I was supposed to do—I was not usurping his role). And as the process dragged on, Jamie became visibly depressed and withdrawn.

Jamie's caseworker and the other MH/ID person left the room to tabulate the results and render an assessment of Jamie's eligibility for "competitive employment" (paid work). Jamie curled into himself on his chair. I had never seen him like this; even when he was sad about his brother or his hanging-out skills, he was always feisty. Now he just seemed defeated.

I came over to sit next to him and put my arm around his shoulders. "Jamie, sweetie," I began. "You are such a wonderful kid and I am so proud that you are my son. This is why I always say '*Je suis tres, tres fier.*' Because I am."

# *Care Planning....How about a Conversation about What Would Help?*

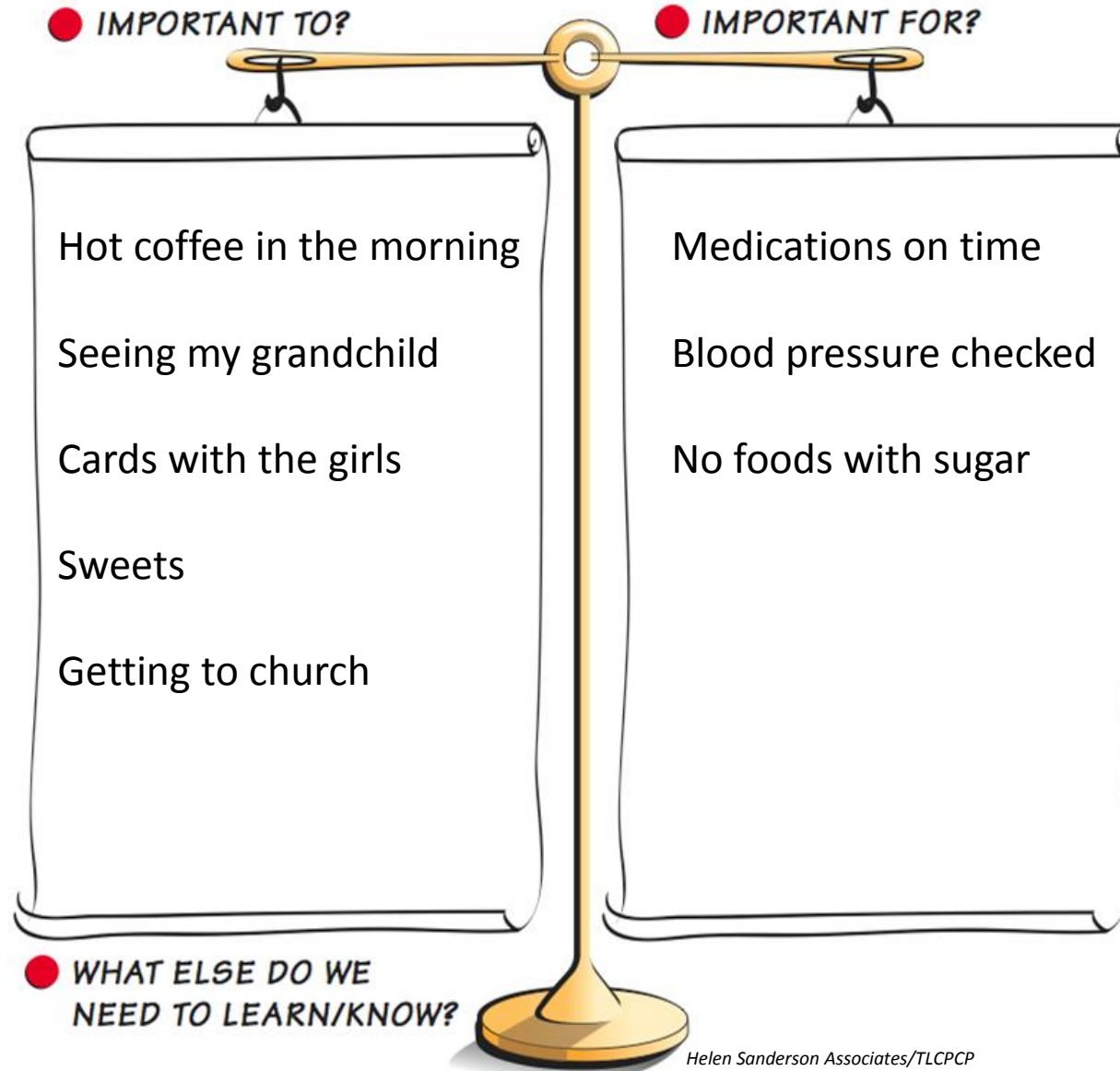
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What is **important to the person**? People, activities, continuing routines and rituals, possessions, traditions, experiences.

What is **important for the person** to be healthy and safe?

Plan to saturate life with things that the person enjoys, treasures, prefers.

# ***SORTING IMPORTANT TO/FOR***



*Helen Sanderson Associates/TLCPCP  
Created by The Grove Consultants International*

# *Service Delivery – the Third Conversation that is On-going*

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**Successful Person-centered Services depends on**

- ❖ Training staff to use person-centered language and behavior
- ❖ On-going staff mentoring and coaching
- ❖ Rewarding staff for using person-centered practices

# *Measuring Outcomes – The 4<sup>th</sup> Conversation*

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**Are we doing what is important to the person?**

Activities; people; routines; possessions; experiences

**Are we doing what is important for the person?**

- Is the person healthy and safe?

**Is the person happy with life?**

# *National Core Indicators*

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Intellectual and Developmental Disabilities



Aging and Disabled

<http://www.nationalcoreindicators.org>

# NCI Overview

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NCI is a performance measurement system that enable states to make policy and funding decisions to support practices that work for people.

- Collaboration between NASDDDS – HSRI and participating state agencies
- NASUAD joined the partnership in 2013 to develop NCI-AD
- Launched in 1997 in 13 participating states
- 40 states (including D.C.) and 22 sub-state regions and counties participate in I/DD NCI
- Data collected annually on 12,000-20,000 people and an unparalleled 17-year database
- 12 states to launch NCI-AD in 2014-15
- Support from the HHS Administration on Community Living

# *NCI System Performance Measures*



## Individual Outcomes

- Employment
- Community Participation
- Choice & Decision making
- Personal Relationships



## Family Outcomes

- Choice and Control
- Family Involvement
- Information & Planning
- Access, community connections



## Health, Welfare, System

- Health and Welfare
- Respect for Rights
- Medications
- Safety
- Service Coordination
- Staff Stability



# *Person-Centered Funding*

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- Fund services that make a difference
- Enable people to have control over how funds are spent and what services they receive
- Allow for the unexpected need - exceptions

# *Family Centered Practices*

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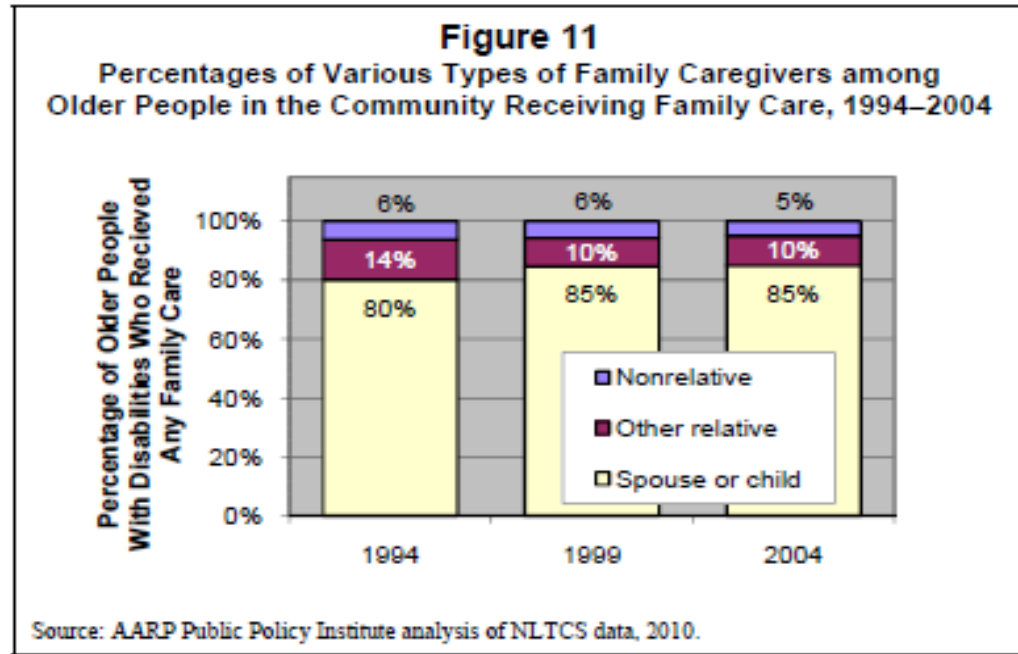
*Family are those people who...consider themselves a family (whether or not they are related by blood or marriage) and support and care for each other on a regular basis. This is not dependent on where they live.*

Turnbull and Turnbull, KU Beach Center

*Family centered supports encompasses the belief that the family is at the center and the service providers are collaborators.*

Carl Dunst and Carol Trivette

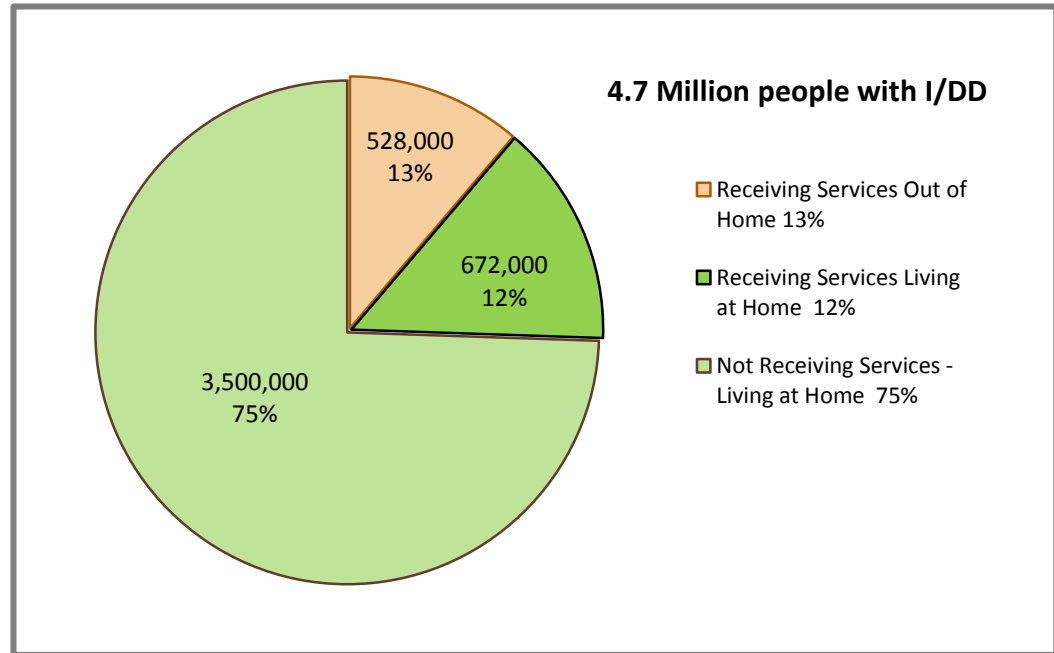
# Family Caregivers are the Nation's Long Term Care System



85% of older family care recipients receive care from their spouses or children.

2 of every 5 adults care for a loved one who is sick or disabled.

36% of people 18-29 are caregivers.



**89% of People I/DD are Supported by Family**

# *Family- Centered Help Giving Practices*

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Research tells us that two kinds of support behavior that contribute significantly to good family outcomes

1. Listening to and being responsive to family priorities
2. Helping families learn skills to obtain desired resources and supports

Carl Dunst and Carol Trivette

# Take a Life Course Perspective



# *Ethical Issue: Training and Support for the Supporters*

It is crucial to provide ongoing supervision from a clinician with expertise in family dynamics to identify issues as they emerge, to help staff be aware of their feelings and reactions, and to review ethical standards, and act accordingly.

- ❖ **A staff member in home on a daily basis begins to be seen as one of the family. Boundaries can be easily crossed, as families share more and more and as staff members see the family in every aspect of home life. Families may begin to**
  - ask for additional help, like child care,
  - suggest social contacts, invite staff members to family events, birthday parties
  - give gifts to staff, and staff may want to give gifts to family members
  
- ❖ **Staff members may become emotionally involved in family members' lives**
  - pulled into marital disputes, and privy to private conversations
  
- ❖ **Staff members may develop strong feelings about the family's**
  - ways of parenting, housekeeping, financial practices

**and these feelings may affect the staff members' interactions with the family, making it harder to maintain their role.**

Early Start Denver Model  
Sally J. Rogers and Geraldine Dawson

*Donald M. Berwick, MD, MPP*  
*Yale Medical School Graduation Address May 24, 2010,*

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But, now I will tell you a secret – a mystery. Those who suffer need you to be something more than a doctor; they need you to be a healer. And, to become a healer, you must do something even more difficult than putting your white coat on. You must take your white coat off. You must recover, embrace, and treasure the memory of your shared, frail humanity – of the dignity in each and every soul. When you take off that white coat in the sacred presence of those for whom you will care – in the sacred presence of people just like you – when you take off that white coat, and, tower not over them, but join those you serve, you become a healer in a world of fear and fragmentation, an “aching” world.....