

UNIVERSITY OF MIAMI  
SCHOOL of EDUCATION  
& HUMAN DEVELOPMENT



# Loving well

**Living with a person with FSHD**

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# Well-Being

*Experiences of pleasure  
and purpose, over time,  
in “i coppe” domains of  
life*

# Domains of Well-Being

- **I**NTEPERSONAL
- **C**OMMUNITY
- **O**Ccupational
- **P**hysical
- **P**sychological
- **E**conomic

# Well-Being

## PLEASURE

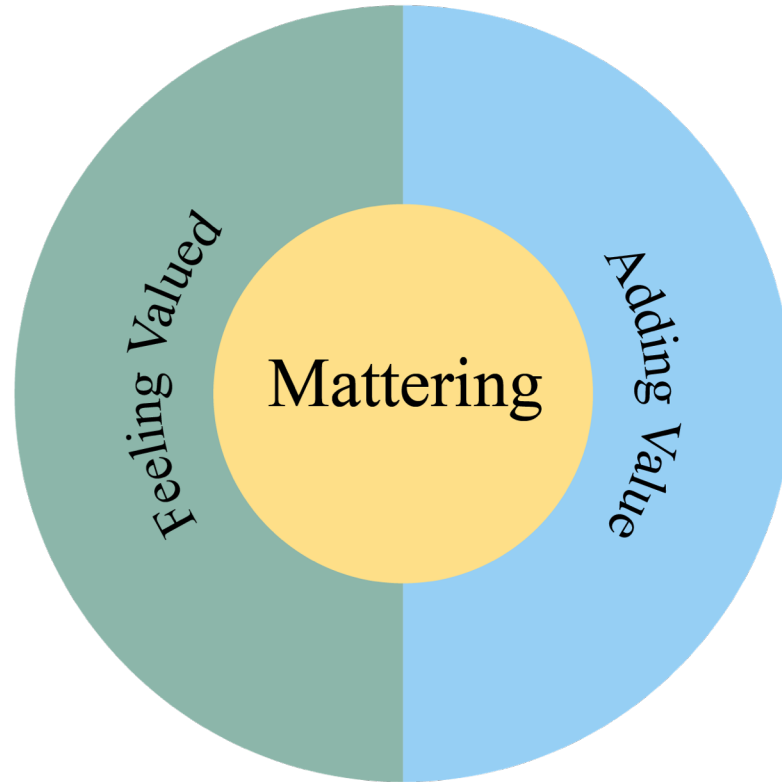
- Joy
- Humor

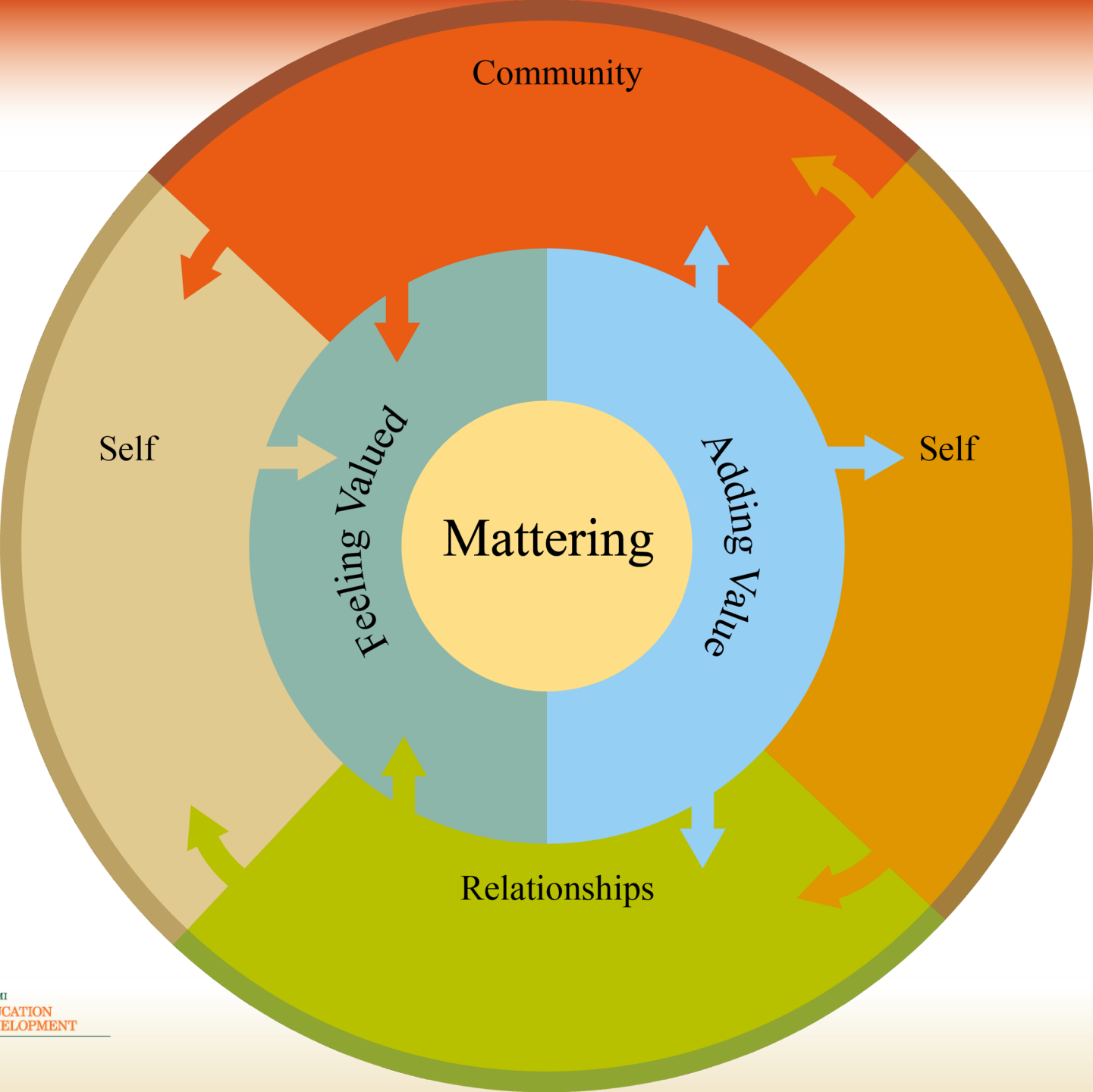
## PURPOSE

- Mattering
  - feeling valued
  - adding value

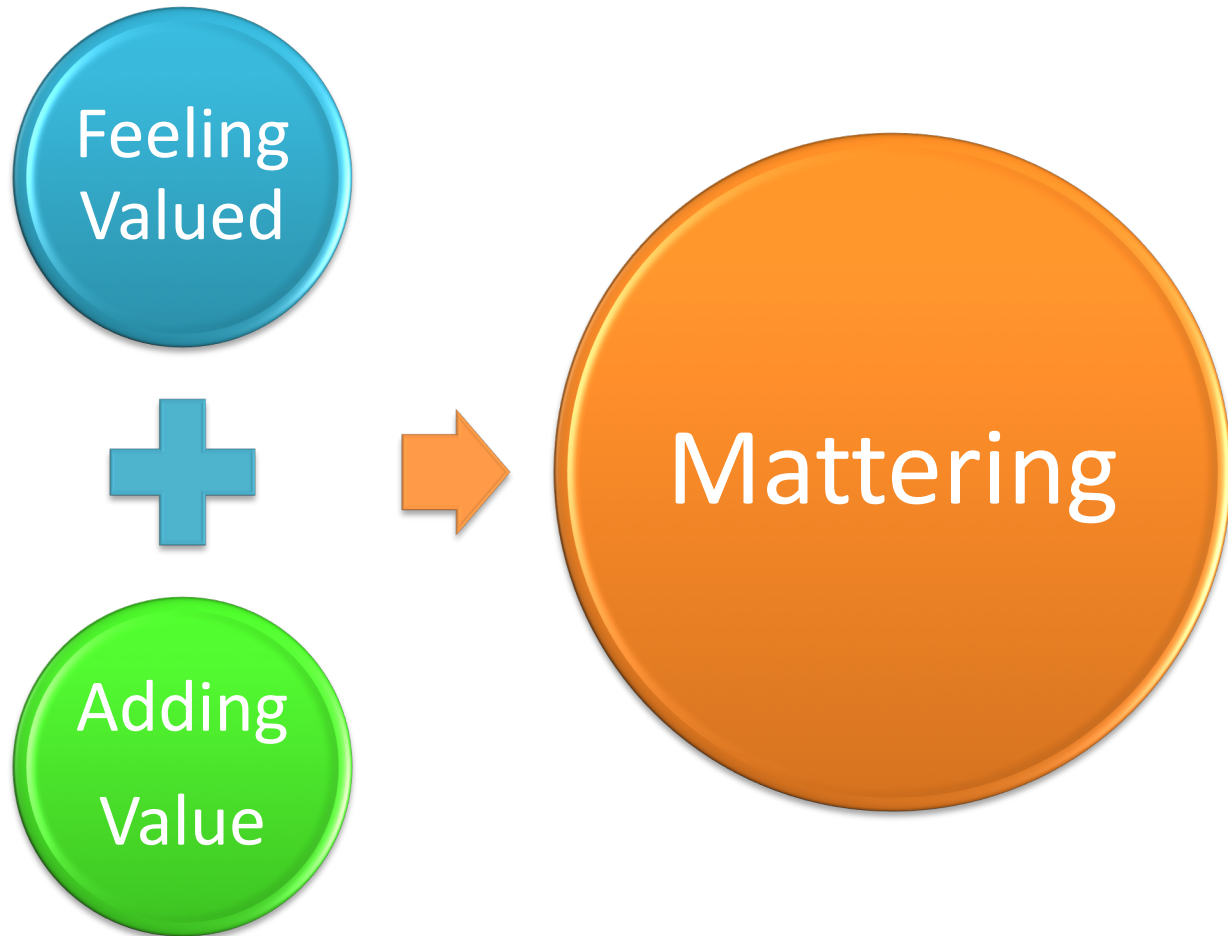


# Mattering

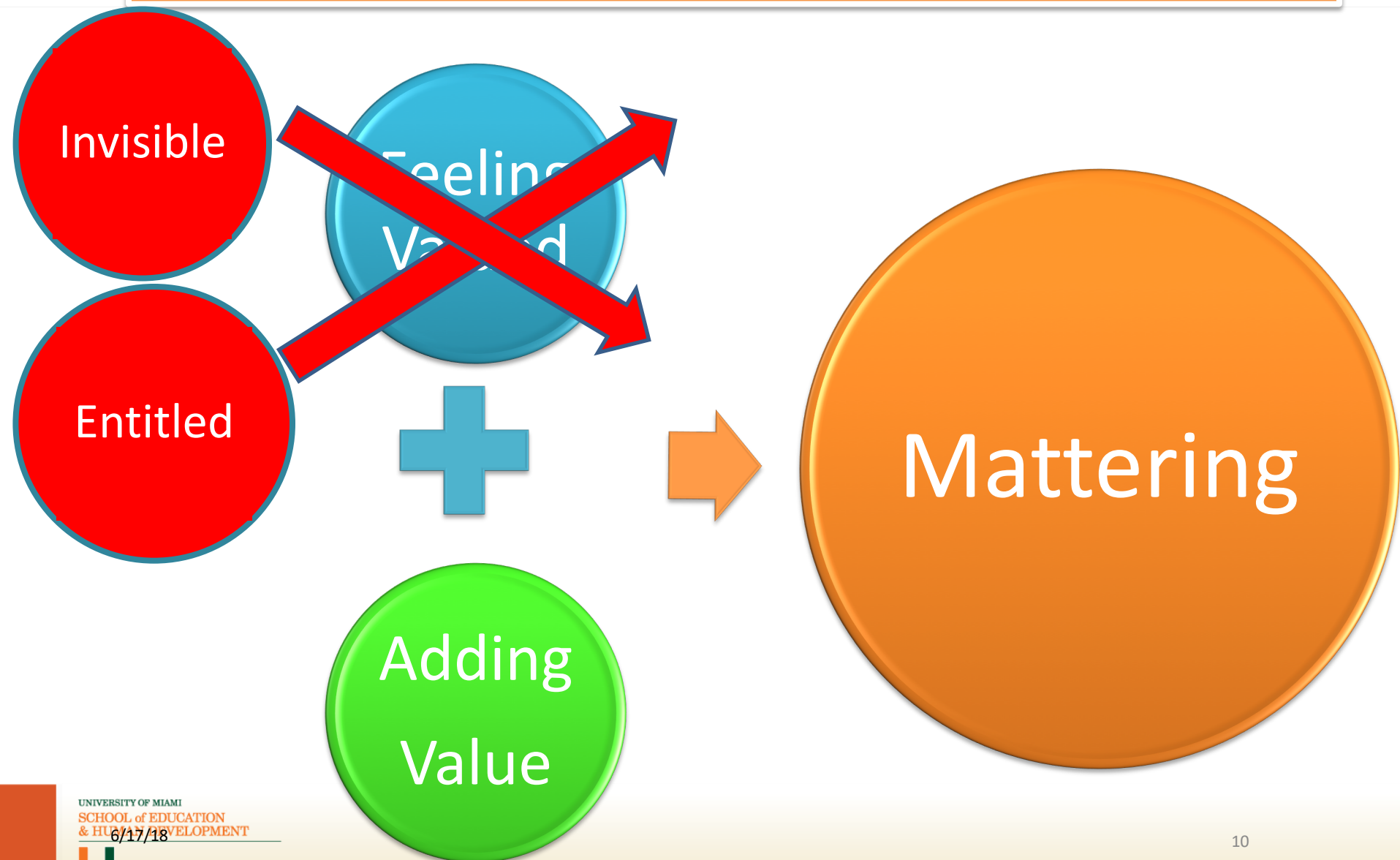




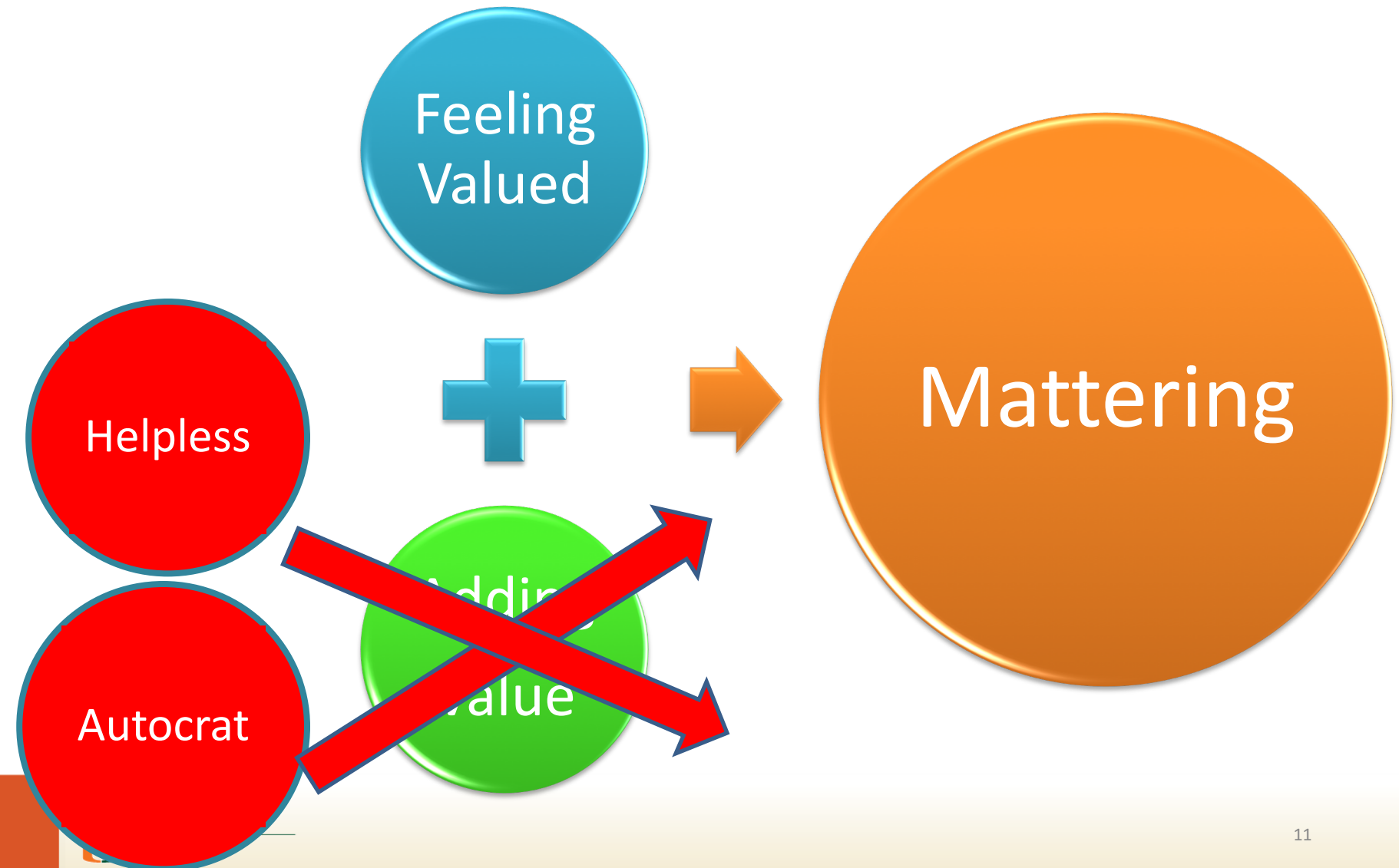




# Threats to Feeling Valued



# Threats to Adding Value



# Mattering in Loving Well

- How do you experience mattering in living with a person with FSH?
- How do you feel valued?
- How do you add value?



# Challenges in Loving Well

- What challenges do you experience in living with a person with FSH?
- What prevents you from feeling valued?
- What prevents you from feeling that you are adding value?

# Reciprocity

- Reciprocity is important in all relationships
- Rigid roles as caregiver or care receiver can lead to stigma and stereotypes
- Both parties entitled to express and fulfill basic human needs

# Dignity

- Dignity is one of the highest human values
- Pity does not foster dignity
- We gain dignity not just by feeling valued, but also by opportunities to add value
- Person with FSH, like the rest of us, is seeking to add value, not just to be in “recipient” role

# Creativity

- There is only one family in the world with the particular context of your life.
- You know your family situation best.
- Embracing rigid social norms of what it means to be happy can limit your fulfillment in life
- How can you turn this situation into a unique opportunity for you to make meaning in life?

# Competency

- Understanding a situation is important, but knowing how to deal with it is even more useful
- We need to develop and share skills related to the experience of “mattering”
- What skills can we learn to “love well” when we live with a person with FSH?

# Competency = Skills in drivers of change

- **B**EHAVIORS
- **E**MOTIONS
- **T**HOUGHTS
- **I**NTERACTIONS
- **C**ONTEXT
- **A**WARENESS
- **N**EXT STEPS

# Domains of Well-Being

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# BET I CAN: Seven scientific principles to promote well-being





# BET I CAN STRATEGIES



# BET I CAN



COPE WITH NEGATIVE  
EMOTIONS  
COLLECT POSITIVE  
EMOTIONS

# BET I CAN



# BET I CAN



# BET I CAN



READ THE CUES  
CHANGE THE  
CUES

# BET I CAN

KNOW  
YOURSELF  
KNOW THE  
ISSUE



# BET I CAN

MAKE A PLAN  
MAKE IT STICK





help

progress

## Fun For Wellness

### Table of Contents

<b>Introduction</b>	Overview .....	Go	100%	
<b>1) Behaviors</b>	Set a Goal.....	Go	25%	
	Create Positive Habits....	Go	44%	
<b>2) Emotions</b>	Cope with Negative Emotions	Go	33%	
	Collect Positive Emotions	Go	30%	
<b>3) Thoughts</b>	Challenge Assumptions	Go	50%	
	Write a New Story.....	Go	40%	
<b>4) Interactions</b>	Connect.....	Go	42%	
	Communicate.....	Go	43%	
<b>5) Context</b>	Read the Cues.....	Go	30%	
	Change the Cues.....	Go	40%	
<b>6) Awareness</b>	Know Yourself.....	Go	93%	
	Know the Issue.....	Go	67%	

# www.funforwellness.com



# Videos



Interpersonal



Physical



Psychological



Economic



Occupational



Community



Psychological

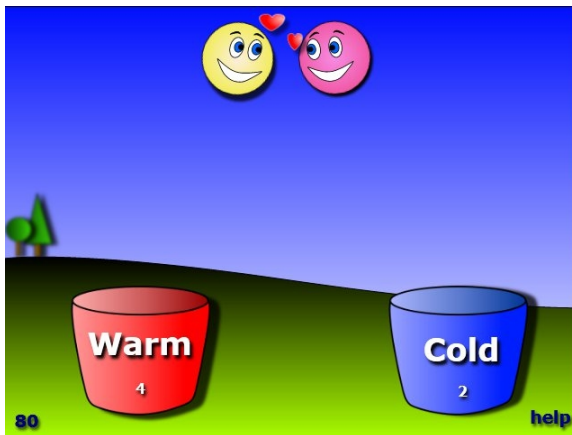
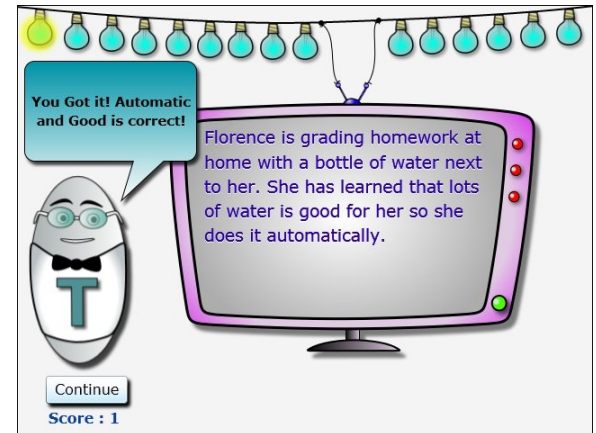
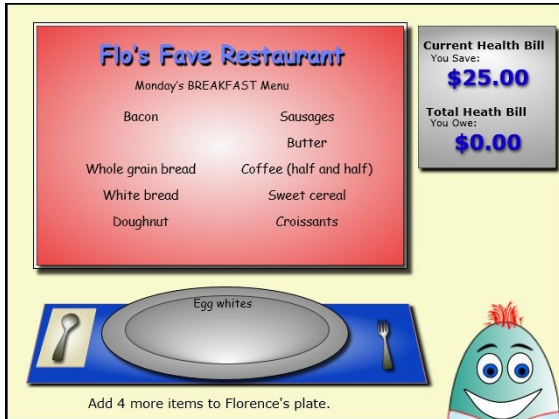


Physical



Interpersonal

# Mini-Games Teach Wellness



# How can you use BET I CAN?

- What skills can you use in your situation?
- Select one and apply it to your life.
- Share with the person next to you.
- Consider sharing with the rest of the group.