



UNIVERSITY CENTER FOR
EXCELLENCE IN
DEVELOPMENTAL
DISABILITIES

University of Connecticut
Center for Excellence in Developmental Disabilities
Consumer Advisory Council
February 2, 2021

Meeting Minutes

CAC Council Members in Attendance:

Emily Ball	Molly Cole	Allyson Powell
Julie Ball	Win Evarts	Deb Richards
Chris Blake	Nanfi Lubogo	Michelle Weaver
Scott Brown	Walter Glomb	
Mary Beth Bruder	Keith Mullinar	Karen Annis - Presenter

UCEDD Staff in Attendance:

Caitlin Clarke	Megan Morariu	Bingbing Zhang
Corrine Dunbar	Linda Rammler	Tara Viens
Elizabeth Fitter	Sarju Shah	
Christine Jozef	Tracy Smith-Michnowicz	

The meeting began via Zoom at 9:35 am.

1. Introductions and Updates

Attendees introduced themselves.

Announcement of Daria Smith's passing. Daria was the director of the state independent-living council and CAC member. She was also the point-person who coordinated our cross-disciplinary life-alliance among many other project and initiatives. She was a hard-worker with impeccable values. She passed away from cancer and leaves behind her son, Jayden. We will discuss a memorial to honor her at a later date.

Mary Beth also announced we lost Tim, the son of Linda Rammler, a staff member at the UCEDD. Tim was a child with disabilities who had learning-challenges and was extremely resilient. Linda wrote a beautiful obituary that we can share if anyone would like to read it.

Mary Beth asked for a moment of silence to honor Daria and Tim, as well as those we lost to Covid this year.

2. Updates for UCEDD

Mary Beth announced that the UCEDD is in the process of applying for a 5-year LEND grant over the next two weeks. LEND has trained over 100 graduate students from social work, nursing, public health, speech and language pathology, audiology, and special education. Now in final year of current 5-year grant and hoping for another 5 years.

The UCEDD also has a collaborative grant with the UConn School of Psychology to train special educators and school psychologists to work with children with extreme learning challenges.

a. Partnership with DDC

Mary Beth explained that one of the biggest collaborations the UCEDD has is with the Council on Developmental Disabilities (DDC). Molly Cole and Linda Rammler presented on these exciting collaborations (PowerPoints included at end of minutes).

Memoranda of Agreement (MOA) #1:

Molly explained that they have established the “Partners in Policymaking” Leadership Academy and the “Building a Great Life” Series.

“Partners in Policymaking” – An intense leadership training. Each participant must complete a project outlined by the DD Council. Will graduate attendees as long as they meet all of the training requirements. The Leadership Academy mirrors Partners in Policymaking in a more condensed form for community leaders, providers, and policymakers.

“Partners” Topics include:

- History of people with disabilities, independent living, and parent movement
- Benefits and values of inclusion, including early intervention and inclusive post-secondary education
- Employment
- Self-directed/person-centered planning
- Legislative process and meeting with legislators
- Community-organizing
- Working with the media
- Dignity of risk
- Parliamentary procedure and effective meetings
- Effective advocacy
- Community resources

These trainings will all be held via Zoom twice a month (on Fridays from 1-4 and Saturdays from 9-3).

“Building a Great Life” (BAGL) – Promoting community-living and good lives for all people in the community of their choice. A series of webinars starts February 11th -- currently 150 people registered for that webinar. All webinars will occur from 6:00 – 7:30pm via Zoom.

Webinar topics include:

- Risk and Dignity of Risk
- Community Life: Friendships, Relationships and Belonging
- Disability Considerations in Building a Livable Community
- Financial Literacy: Benefits, ABLE Accounts
- Employment Overview
- Employment in Connecticut
- Housing Options
- Housing Rights
- Supported Decision Making

BAGL still planning a statewide conference and reserving a hotel for September 9th, but may need to move to November due to COVID.

MOA#2

Linda described that under this MOA there are many things being worked on:

- Developing a “Think College” Manual, based on past report from Goodwin University. Handbook contains all the steps, including: planning process, resources for faculty, and educational peer-navigators. The DD Council will print and disseminate Handbook, due at the end of February.
- Supported Decision-Making Coalition – looking at alternatives to guardianship. A guidebook is being created and training and outreach is planned.
- Parent Leadership and Encouragement collaborating with ARC-CT. Currently recruiting a stakeholder group and developing a resource website.
- Self-Directed Supports collaborating with ARC-CT. Doing research on data, policies and practices in other states, with a focus on practical information for families and people with disabilities on how to direct their own supports.
- Training on “Postsecondary education” (PSE) for families and people with disabilities. Three trainings almost ready to launch on Think College: (1) for those affected by intellectual disabilities, (2) Thinking College for other disabilities, and (3) Adulting: Thinking College.
- Training on “Customized Employment” for families and people with disabilities. Two trainings almost done and ready to launch via recording presentations.

Walt Glomb suggested that everyone read the DD Act because it is essential to everything we do. The DD council is primarily a grant-making organization and does the most work with the greatest impact when we (third-parties) participate and have federal funds. The challenge is finding people who share our values and are willing to do the work with “boots on the ground.” This is why so much work has landed at the UCEDD. COVID cancelled many activities and the DD Council & UCEDD lost some ground and are

playing catch-up at this point. Walt appreciates the partnership with the UCEDD, which is critical to the work that is being done.

b. Early Childhood and Other UCEDD Activities

Mary Beth gave a review of other activities occurring at the UCEDD:

- Finishing up the Early Intervention Specialist Program (EISP)- 80 people trained for this rigorous program, considered a Master's-level class. Just started our last of 10 and will write again in spring to continue.
- Masters in ASD in Early Childhood – Master's in Special Education program through the Ed Psych program at NEAG School at UConn. This is a five-year grant and we currently have nine students currently enrolled. At the end of the five years we will have 45 graduates.
- Early Childhood Intervention Doctoral Consortium (ECiDC) – Doctoral program funded to increase capacity of Higher Education. This program consists of scholars from 10 universities across the country. There are 18 students for Cohort 1 and 10 students for Cohort 2.
- “Act Early Learn the Signs” – CDC-funded project, translated materials to Spanish and Portuguese. Have a partnership with DCF, training them to recognize the signs of Autism.
- AUCD SIG – A special interest group that offers monthly webinars nationally.
- Early Childhood Personnel Center (ECPC) –Technical assistance center working with state systems and higher education institutes to build their capacity. Worked with 37 state leadership teams, 136 faculty from institutes of higher education in 35 states, 52 family members from 27 states on personnel preparation, and offered intensive support to 16 states to build a comprehensive system of personnel development (CSPD).
- Disability Certificate in Public Health – Comprised of 4 courses.
- Medical Students – Preparing medical students on individual learning.

Mary Beth shared results from a UCEDD survey sent to their entire mailing list in May on the effects of the COVID pandemic. Some of the biggest concerns according to survey results (primarily mothers were the ones who filled out the survey):

1. Wellbeing of family members
2. Concern about remote schooling
3. Concern about mental health
4. Concern about physical health
5. Concern about education

Highest needs of COVID – Educational needs, especially for those receiving special education services.

3. Chronic Stress, Mental Health Supports and Self Care Strategies under COVID: For Ourselves and Those with Disabilities – Allyson Powell and Karin Annis
(PowerPoint slides attached at end of document.)

Allison Powell explained that we are living under a very different kind of stress. Not only are we dealing with the COVID pandemic, but our stress is also layered in politics, news, racial issues, environmental issues, on top of work and personal stress. The UConn Employee Health Department has seen many types of stress, especially as we adjusted to working from home so quickly, and as we transition back to offices that look very different from those we left in March.

Karen Annis from the UConn Employee Assistance Program (EAP) presented on “Stress Management during COVID-19.” Karen explained that we are all used to the “new normal” The case resurgence news may cause us to re-experience emotions and trauma related to the first wave.

Many parents report stress with kids learning at-home while parents work remotely as well. Another problem is that our usual stress-relievers (church, dinner out, going to movies) are not available. Feeling chronically overwhelmed can lead to escape behaviors (substance-abuse or binge-watching), so it is important to keep an eye on people who seem to be “checking-out.” We need to remember that we are all in the same storm, but not all in the same boat. Some people were not good emotionally before the pandemic started, and some may be dealing with losing a loved-one to COVID. We are also in a different boat if we have children with disabilities and are navigating their new learning styles with remote learning. Underserved families are also very vulnerable due to limitations that COVID has put on all of us.

Dealing with stress is better when people feel connected to others and feel some sense of control. It is important to check-in with family and friends to make sure they are doing okay. Examples to keep connected are exchanging recipes or lockdown tips, group discussions on movies or books, online games or escape rooms, and volunteering for virtual community efforts.

It is ok to not be ok all of the time. The temptation is to tell people that you are fine, but it is important to verbalize if you are struggling with certain things. Vocalizing your feelings allows others to recognize they are going through it as well.

Allison stressed that the EAP can be for anyone. There is a misconception that it is just for employee issues. The EAP provides access to a counselor at no cost and can help family members.

Mary Beth asked if there were any groups for family-support. Allyson said no, not right now but they have been working with groups for pre-teens and teens have been very successful.

Next Steps:

The next CAC meeting TBD June or July.

Meeting adjourned at 11:30 a.m.

Respectfully submitted,

Christine Jozef
University of Connecticut Health Center
Center for Excellence in Developmental Disabilities

Memoranda of Agreements with the CT Council on Developmental Disabilities

MOA #1

1. Establish Partners in Policymaking Leadership Academy.
2. Create a website and webinar series that will brand the Building a Great Life concept.
3. All deliverables for all MOA activities are due by September 30, 2021 as per this MOA.

Establish Partners in Policymaking Leadership Academy

- Partners in Policy-Making
- Partners in Leadership
 - Community Leaders
 - Provider Agencies
 - Policy-makers

Partners in Policymaking

- Classes begin February 19th and will be held Friday and Saturday twice monthly via Zoom.
- 31 participants have been selected.
- All participants will receive Zoom training February 4 or 5 to ensure they can navigate the class and to ensure that they have adequate technology and technology skills.

Partners in Policymaking (cont.)

- Meeting support and support between sessions will be provided by faculty advisors.
- All competencies of Partners will be addressed.
- Projects will reflect DD Council priority areas.
- Graduation will be held in September.

Partners Leadership Topics

- History of people with disabilities, independent living and parent movement
- Benefits and values of inclusion including early intervention and inclusive post-secondary education
- Employment
- Self-directed/person-centered planning
- Legislative process and meeting with legislators

Partners Leadership Topics (cont.)

- Community organizing
- Working with the media
- Dignity of risk
- Parliamentary procedure and effective meetings
- Effective advocacy
- Community resources

Partners in Leadership

- Audiences will include community leaders, providers and policymakers at state and local levels.
- Topics will mirror Partners in Policymaking, but content will be condensed to respect time constraints of these audiences.
- These will be planned for virtual access at this time, with the potential to do some face to face if protocols permit.
- Linda is coordinating. These will be launched as described and completed by 9/30/21.

Building a Great Life

- Established under two state-wide conferences.
- Branding Building a Great Life as a movement to support good lives for all people in the community of their choice.
- Will be planned and implemented with a core committee who will also plan the next conference.

Webinar Series and Website

- A series of webinars will be held from February through September.
- Each webinar will be supported by resources and documents on the BAGL website, so that there is a repository for all materials.

BAGL 2021 Webinar Topics

- Risk and Dignity of Risk
- Community Life: Friendships, Relationships and Belonging
- Disability Considerations in Building a Livable Community
- Financial Literacy: Benefits, ABLE Accounts
- Employment Overview
- Employment in Connecticut
- Housing Options
- Housing Rights
- Supported Decision Making

Calendar of Webinars

- Webinars <https://uconnucedd.org/bagl/>
- All webinars are from 6-7:30 PM and are offered at no cost
- First webinar is February 11th and features Sheli Reynolds discussing “The Richness of Living a Life That Includes Risk”
- Registration:
<https://www.eventbrite.com/e/building-a-great-life-the-richness-of-living-a-life-that-includes-risk-tickets-136037970231>

BAGL Conference

- As of now, we are still planning to hold another statewide conference.
- Currently set for September 9th, but may need to be moved to November pending health protocols.
- The same planning committee will help plan the conference.

MOA #2

1. Think College Manual
2. Supported Decision-Making Coalition
3. Parent Leadership and Encouragement Project
4. Self-Directed Services
5. Postsecondary Education trainings
6. Customized Employment/Employment trainings
7. All MOA #2 deliverables are due by September 30, 2021 except where noted

Think College “How-to Manual” based on GU’s experience

- Past report to CAC on Goodwin University
- Will open to students with ID in Fall 2021
- Handbook contains GU’s steps, e.g.,
 - Planning process
 - Department-by-department considerations
 - Faculty, Educational (peer) Navigators, Students
- DD Council will print to disseminate
- Due: Feb. 28, 2021

Supported Decision-Making (SDM) Coalition (incl. Molly)

- Alternative to Guardianship
- Activities:
 - Guidebook (in process)
 - Letter to LEAs (completed)
 - On-going Collaboration meetings
 - Policy work
 - Website content/development
 - Training and Outreach
- Adulting module on Citizenship, Legal Issues, and Finances includes SDM in revision phase

Collaborate with Arc CT re: PLE Project

- Parent Leadership and Encouragement
- Recruiting stakeholder group
- Developing a website of resources
- Arc CT has retained a Project Coordinator
- Scholarly paper for UConnUCEDD.org in process
- Goal: Have stakeholder meeting and begin website development by May 31, 2021

Collaborate with Arc CT

re: SDS

- Self-Directed Supports
- Research on data, policies, practices in other states
- Focus on practical information for families and people with disabilities
- Adulting module: How to self-direct your own supports in editing process

Training on PSE for families and PWD

- PSE stands for Postsecondary education
- Includes Think College Initiative (not funded 😞)
- Three training approaches almost done:
 - Think College (national model) for those affected by ID
 - Thinking College for other disabilities
 - Adulthood: Thinking College include Think College
- Ready to launch via recording presentations

Training on CE/Employment for Families and PWD

- CE = Customized Employment
- CIE = Competitive Integrated Employment
- All CE is CIE
- Two training approaches almost done:
 - Videotape of summer 2020 presentation to PATH/Family Voices for website
 - Adulting module: CE/Employment
- Ready to launch via recording presentations

Questions?



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For More Information, Contact:

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Stress Management During Covid 19

UConn
HEALTH

EMPLOYEE ASSISTANCE
PROGRAM

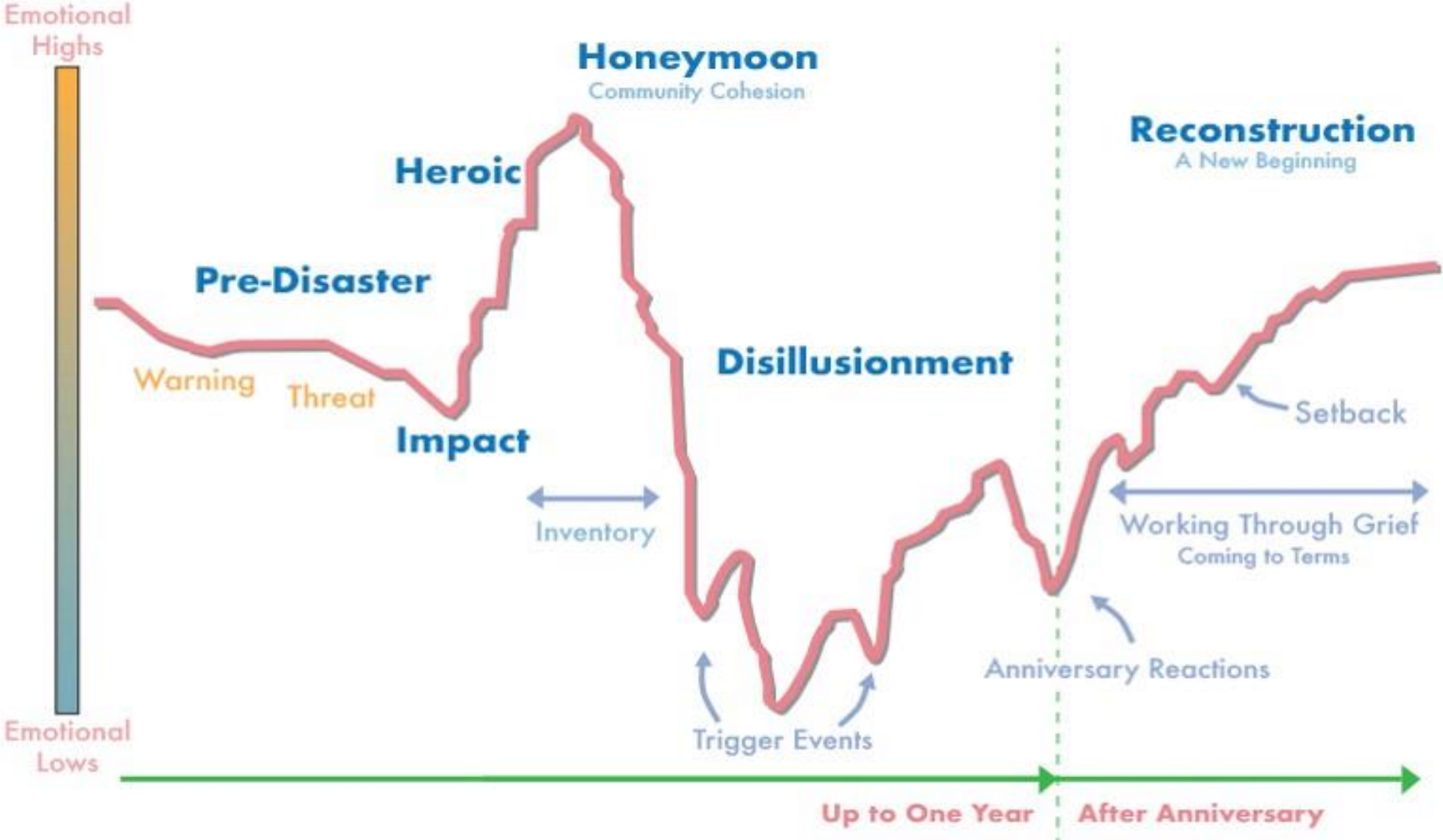
Where are we now?

- People have been faced with **high** levels of stress, change and loss for a **prolonged** time
- After the initial crisis, we adjusted to some extent to our “new normal”
- Resurgence of cases may cause us to re-experience emotions and trauma related to first wave
- Our usual coping mechanisms have been interrupted and there are additional stressors and challenges
- Many are feeling tired, frustrated and burned out and are struggling to regroup
- Though vaccination has begun, the future/endpoint is still uncertain

What the research is showing...

- Increased rates of depression, anxiety, substance use disorders and trauma-related symptoms
- Interpersonal/domestic violence has increased by 20%
- Groups who have been most impacted include:
 - Adolescents/Young Adults (ages 13-23)
 - Racial/Ethnic Minorities
 - Essential Workers
 - Unpaid Adult Caregivers
 - Individuals with history of mental health issues

Disaster Recovery & Response



Burnout

- Exhaustion due to prolonged stress
- Feeling overwhelmed, emotionally drained, 'empty'
- Feeling 'every day is a bad day'
- Increased irritability
- Vulnerable to increased relationship conflict
- Physical symptoms – headaches, back aches, sleep disruption
- Escape behaviors

We may be in the same storm,
but we are not all in the same boat



Mental health

“A state of well-being in which every individual realizes their own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to their community.”

~World Health Organization

Mental Health

Emotional Wellbeing

Psychological Wellbeing

How we feel

How we think

How we act

**Stress
managment**

**Academic/
work
performance**

**Decision-
making**

**Social
engagment**

Stress research shows that people do better in ongoing, stressful circumstances when they...

- Feel safe, calm, and connected to others
- Regain a sense of control
- Have access to social, physical, and emotional support
- Have a sense of optimism, faith, hope

**"Alone we can do so little;
together we can do so much."
- Helen Keller**



Staying Connected to Others:



Check in regularly with family and friends

Physical distancing need not mean social distancing. Engage in regular conversations with your friends and family through phone, chat, or video calls.

Exchange favourite recipes or lockdown tips

This is a good time to try new things and explore new hobbies. Exchanging your ideas with others can help you stay engaged and connected.

Host a movie night or a virtual book club

Sharing your interests with loved ones or friends can be both a stress-buster and a distraction from the constant news cycle.

Play virtual games or puzzles together

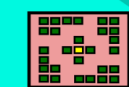
Lose yourself over an evening session of Words with Friends or Virtual Ludo, keeping those brain cells buzzing.

Volunteer for virtual community efforts

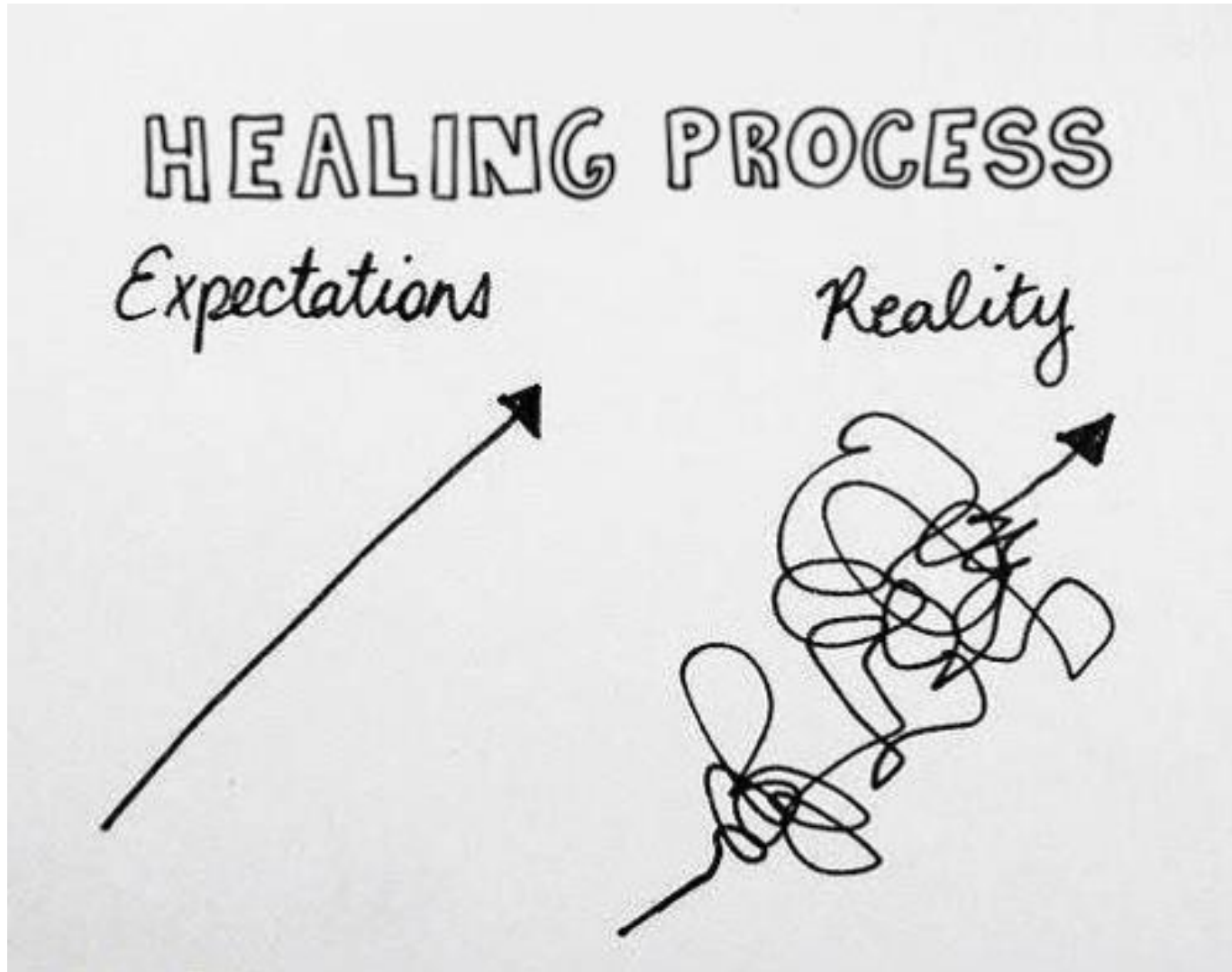
This is a good time to volunteer your services via online means to charities or support groups near you, to help others in a crisis.

Plan virtual get-togethers to celebrate positive occasions

Planning a group video call or coming up with creative digital wishes is a great way to virtually stay in touch with your loved ones



Connection



@PeacefulMindPeacefulLife

It's ok if you thought you were over it but it hits you all over again.

It's ok to fall apart even if you thought you had it under control.

You're not weak.

Healing is messy. And there is no timeline for healing.

— UNKNOWN

Self Care: The Basics



Giving Back

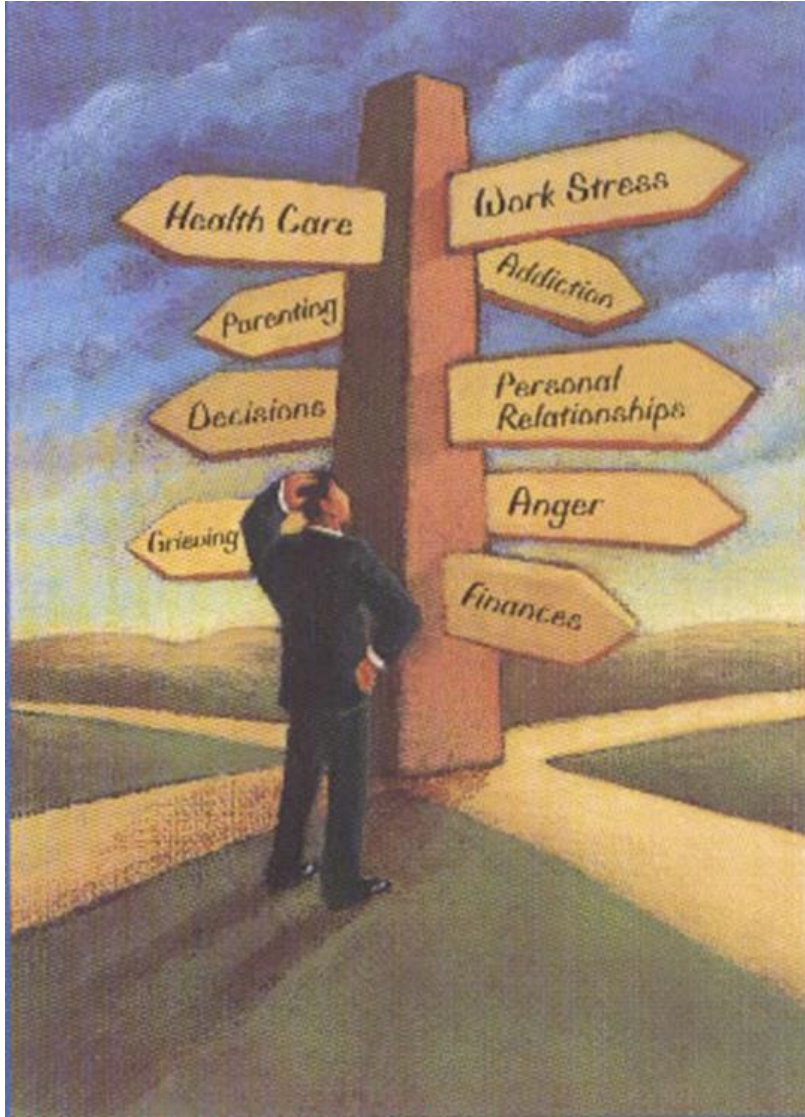


- Decreases risk of depression
- Gives a sense of purpose
- Helps meet others and fosters new relationships
- Helps decrease stress
- Increases physical and mental activity
- Increases life expectancy

Know When You Need More Support



- Changes in sleep or appetite
- Work performance is suffering
- Escape behaviors
- Relationships are strained
- Feeling frustrated, irritable, guilty and can't identify why
- Struggling to regulate your emotions
- Struggling to stay motivated
- Feelings of intense anxiety
- Thoughts of suicide



What the EAP Offers

- Service for any problem
- Access to a counseling professional at no cost
- Quick, convenient appointments
- Availability to family members
- Confidential support
- A pre-screened network

EAP Contact Information

- Call 860-679-2877 or 800-852-4392
- Email: uchc_eap@uchc.edu
- Hours: 8:00am – 5:00pm
- After business hours, if the situation is urgent, call the main number and follow the instructions. You will be connected to the on-call EAP counselor.

