Self- Neglect / Hoarding:
Working with people who are hard to engage

Therapeutic and Social Approaches

Health Care Conferences UK

- hoarding and risk issues relating to hoarding
- preventing the escalation of hoarding
- supporting a person with hoarding behaviour to address underlying cases of hoarding
- supporting the person to change hoarding behaviours
- our experience and lessons from a serious case review

Sheila is self-neglecting

Neighbours report that Sheila appears to have mental health problems, she has been hoarding items in a squat and she is losing a lot of weight. The squat was inhabited by people using Heroin, who left when the electricity was cut off. The living conditions are reported to be very poor. Sheila binge drinks on occasions and has had some falls.

How would services currently respond to Sheila. What would you do?

Your answers will often include:

Everyone wants to refer Sheila on. We have created a world of care management.
We need to return to old fashioned Social Work. Working together to understand and support

Discuss:

- What has happened to this person?
- How does trauma affect a person physically and mentally?
- What does the person need to feel safe?
- What does the person need to feel well?
- What cultural issues may need to be considered?
- What reasonable adjustments might need to be made?
- When I first met this woman she wasn't eating and was dangerously thin. Why might this be?
- What did this story make you feel?
- What would you do differently now?
- What are the priority needs for Sheila?
- How important is it to know her first and focus upon her rather than the environment?

Consider the Power that I have in this situation, the threat that I perceive and the meaning that I derive from your interventions with me

You are not eligible

You don't have a mental health problem, its environmental

You are not motivated

You have missed appointments

You have been unsuccessful

You are intentionally homeless

You don't engage

You are difficult to work with

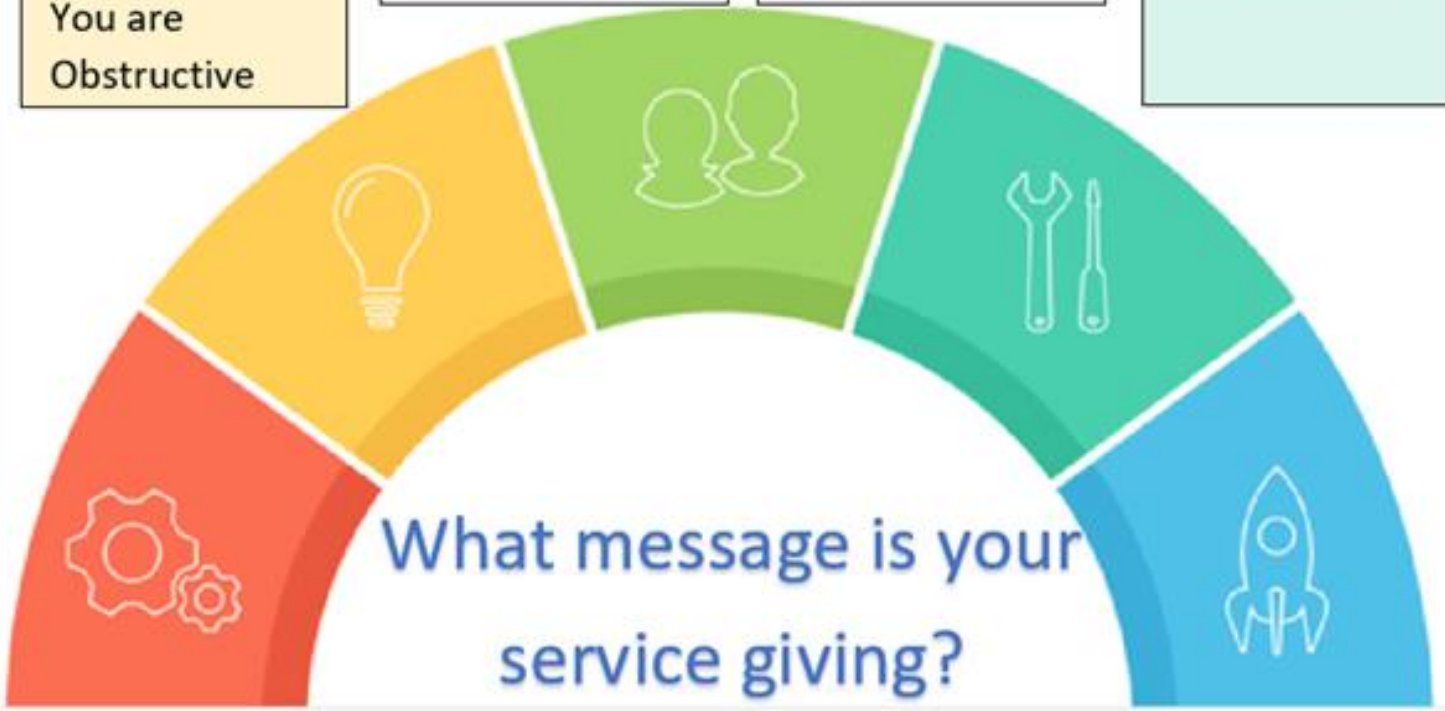
You are Obstructive

This is what I hear. This adds to my rejection, powerlessness, loss, fear, pain and anxiety.

This is what I need to hear. This helps heal my trauma, anxiety, loss, powerlessness.

We can help you

These are coping mechanisms for trauma



What happened to you to make you feel this way about yourself?

Let's look at what you are good at, what skills you have - connection

We can make adjustments to help you to attend or meet with us

Miracle last night – What would things look like?

Self-Neglect

When you look at me you consider what you perceive needs fixing.

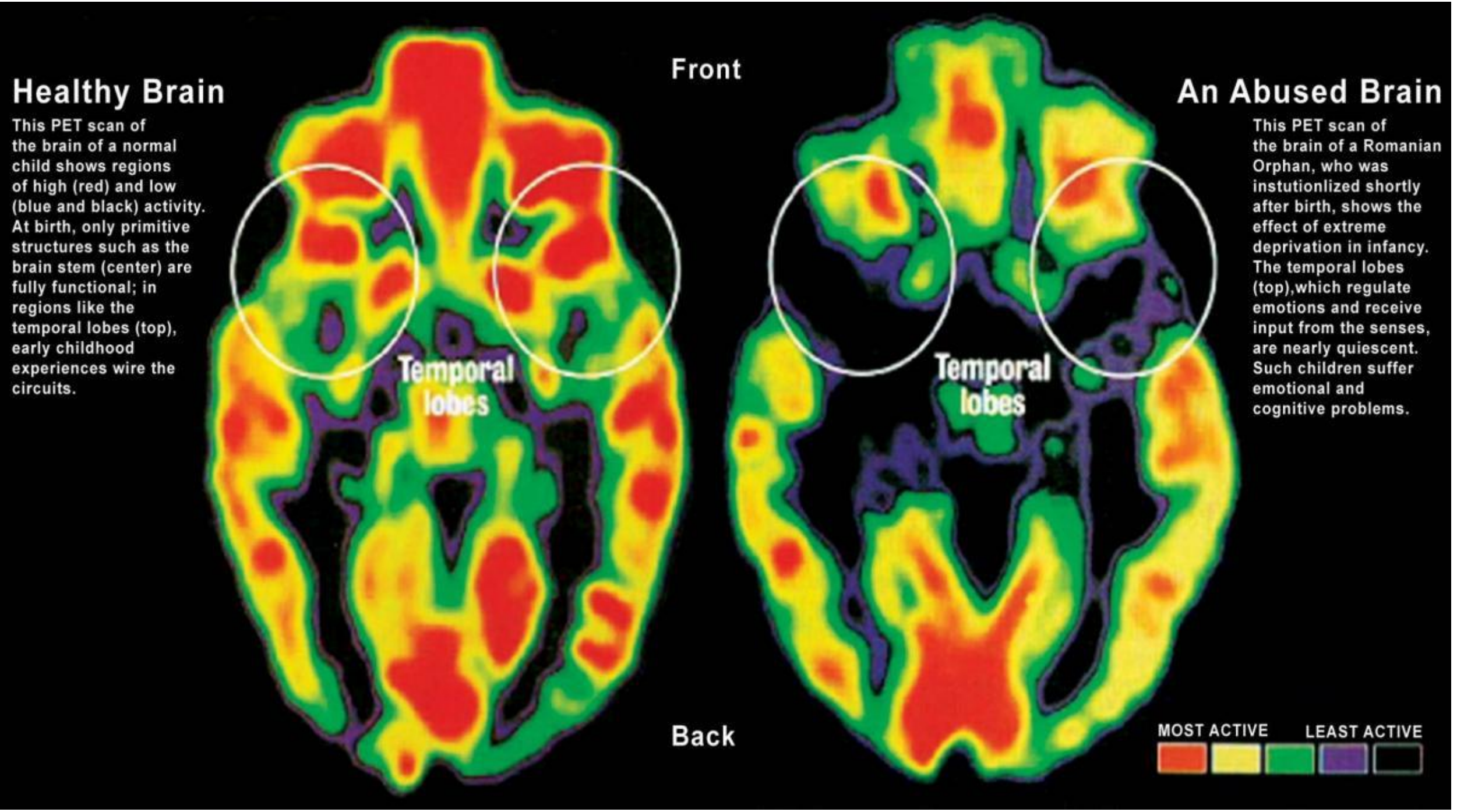
- You want to make my home nice and clutter free, you want to stop me from misusing substances, you want me to get medical care and attention, you want to give me a home.
- Those solutions will not fix me, they will lead me to untold torture and an early death.
- Inside me is such pain and hurt that I can not bear to face.
- I can not trust people because people hurt me, neglect me or leave me.
- I hang on to my objects because I don't care about me, but I care about something, they keep me safe, they are my everything. My objects demonstrate that I am human and I have things that are important to me. They are my one link to the real me.
- If I live in squalor it demonstrates the lack of self-worth I have for myself.
- If I do not attend medical appointments this tells you that I do not care about my body or I am too afraid to attend.
- If I drink to excess I am telling you that I cant manage the feelings, emotions and memories.
- If I live on the streets I have a need to see what the threat is in front of me.

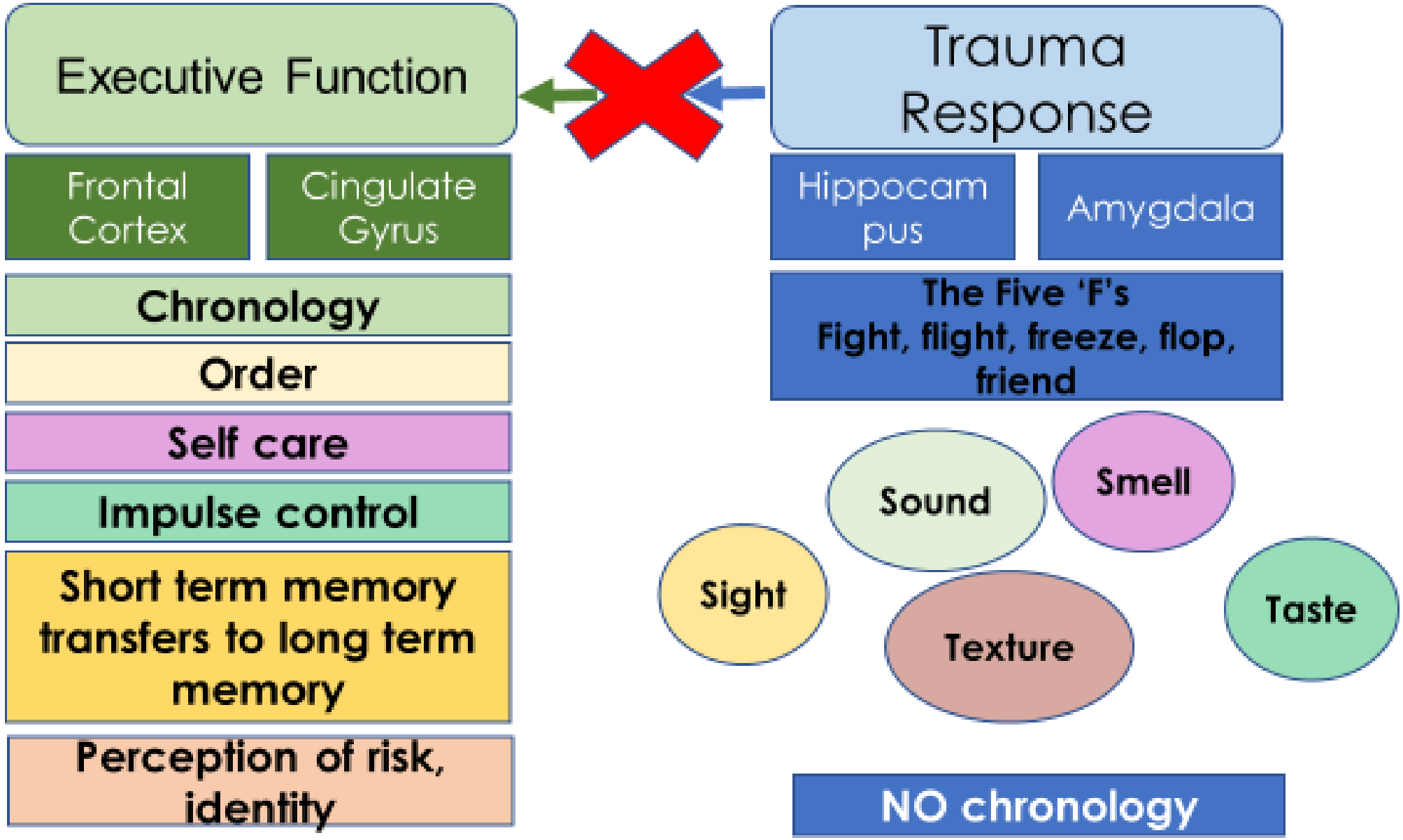
WHAT ARE THESE PEOPLE COMMUNICATING?

Non verbal communications - In real life explore the persons narratives and do not make assumptions. For this exercise draw upon some hypothesis

1. A person isolates themselves socially because..,…… why…….?
2. A person is attached to objects rather than people because…… why……?
3. A person does not care for themselves because…….. why….?
4. A person is suspicious and paranoid because…….. Why…..?
5. A person is anxious because….. why…….?
6. A person is crying unceasingly, curled up in a ball because…….why…….?
7. A person is living on the streets because…… why…..?
8. A person is drinking excessively, or excessively using drugs because……why…..?
9. An aggressive and distressed person is telling you…….. Why……?
10. A child gets involved in crime because….
11. A child becomes aggressive because……..
12. A child takes drink / drugs because…….
13. A child becomes vulnerable to exploitation because……

behaviour as communication- beha (safehandsthinkingminds.co.uk)


Healthy Brain
This PET scan of the brain of a normal child shows regions of high (red) and low (blue and black) activity. At birth, only primitive structures such as the brain stem (center) are fully functional; in regions like the temporal lobes (top), early childhood experiences wire the circuits.
Front
Temporal lobes
Temporal lobes
An Abused Brain
This PET scan of the brain of a Romanian Orphan, who was instutionlized shortly after birth, shows the effect of extreme deprivation in infancy. The temporal lobes (top),which regulate emotions and receive input from the senses, are nearly quiescent. Such children suffer emotional and cognitive problems.
Back
MOST ACTIVE
LEAST ACTIVE


Executive Function
Frontal Cortex
Cingulate Gyrus
Chronology
Order
Self care
Impulse control
Short term memory transfers to long term memory
Perception of risk, identity
Trauma Response
Hippocampus
Amygdala
The Five 'F's
Fight, flight, freeze, flop, friend
Sound
Smell
Sight
Texture
Taste
NO chronology

DIMINISHED EXECUTIVE FUNCTIONING -

1. Activation	2. Focus	3. Effort	4. Emotion	5. Memory	6. Action
Difficulty with: • Organising • Initiating tasks • Prioritising tasks • Planning things • Tasks like self-care and care of the home	**Difficulty with:** • Focussing on tasks • Shifting attention to tasks • Flexible thinking • Adjusting to unexpected change • Rigidity	**Difficulty with:** • Maintaining alertness • Sustaining effort • Processing speed • Maintaining contact • Attending appointments	**Difficulty with:** • Managing frustration, anger, fear etc • Modulating emotions • Keeping feelings in check • Fight, flight, freeze flop responses kick in	**Difficulty with:** • Keeping key information in mind and being able to use the information • Accessing recall • Walking the walk as well as talking the talk	**Difficulty with:** • Impulse control • Self-regulation • Thinking before acting • Substance misuse, hoarding, self-harm etc as survival strategies

Question: If a person is communicating clearly that they are not wanting services can we assume capacity?

NO - The Mental Capacity Act codes of practice identifies that not being able to use the information in employing the skills means that they lack capacity to make the decision.

S4.21 For someone to have capacity, they must have the ability to weigh up information and use it to arrive at a decision. Sometimes people can understand information but an impairment or disturbance stops them using it. In other cases, the impairment or disturbance leads to a person making a specific decision without understanding or using the information they have been given.

Question: If a person is communicating clearly that they are not wanting services can we assume capacity?

S4.22 For example, a person with the eating disorder anorexia nervosa may understand information about the consequences of not eating. But their compulsion not to eat might be too strong for them to ignore. Some people who have serious brain damage might make impulsive decisions regardless of information they have been given or their understanding of it.

Trauma affects the brain so that the person can talk about the components but cant seem to put all of the pieces together to make them work. They are in survival mode

Hoarding Disorder is a compulsive disorder

DSM-5: Hoarding Disorder
Disorder Class: Obsessive-Compulsive and Related Disorders
Persistent difficulty discarding or parting with possessions, regardless of their actual value.
This difficulty is due to a perceived need to save the items and to the distress associated with discarding them.
The difficulty discarding possessions results in the accumulation of possessions that congest and clutter active living areas and substantially compromises their intended use. If living areas are uncluttered, it is only because of the interventions of third parties (e.g., family members, cleaners, or the authorities).
The hoarding causes clinically significant distress or impairment in social, occupational, or other important areas of functioning (including maintaining a safe environment safe for oneself or others).
The hoarding is not attributable to another medical condition (e.g., brain injury, cerebrovascular disease, Prader-Willi syndrome).
The hoarding is not better explained by the symptoms of another mental disorder (e.g., obsessions in obsessive-compulsive disorder, decreased energy in major depressive disorder, delusions in schizophrenia or another psychotic disorder, cognitive defects in major neurocognitive disorder, restricted interests in autism spectrum disorder).

Case law

- [Re E medical treatment EWCOP 1639 - Search (bing.com)]

4.37 For example, a person with the eating disorder anorexia nervosa may understand information about the consequences of not eating14. But their compulsion to not eat might be too strong for them to ignore. Some people who have a brain injury might make impulsive decisions regardless of information they have been given or their understanding of it, which may indicate that they are not able to use or weigh the information.

Executive Functioning

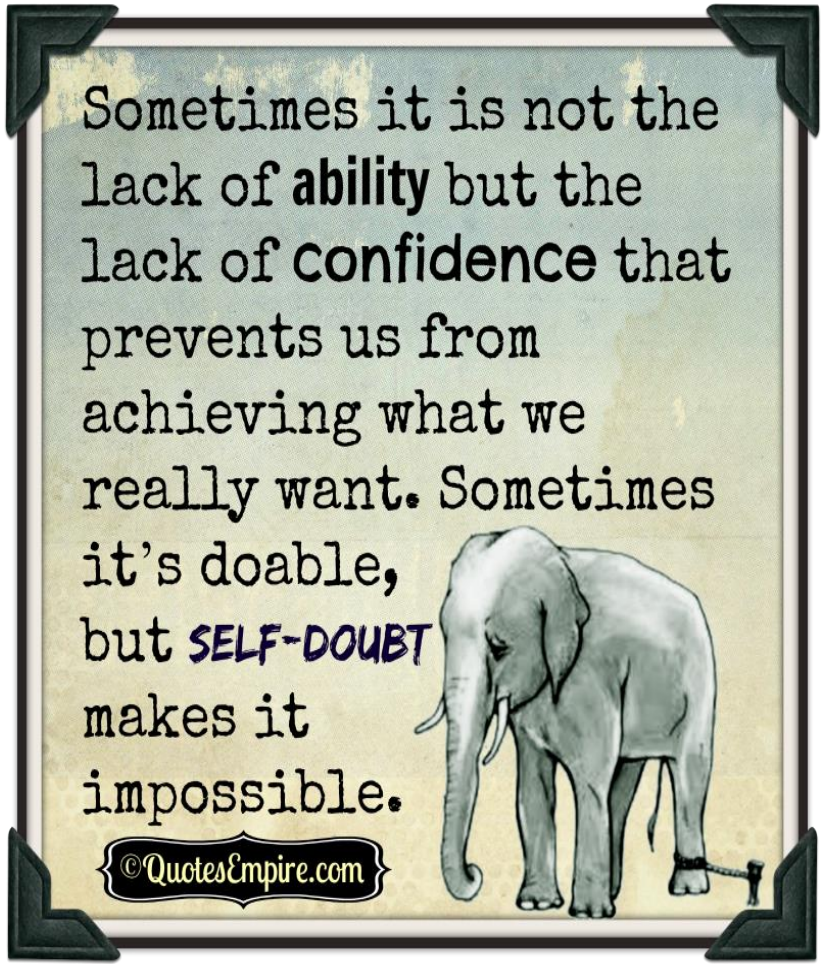
4.38 Another common area of difficulty is where a person with an acquired brain injury gives coherent answers to questions, but it is clear from their actions that they are unable to give effect to their decision. This is sometimes called an impairment in their executive function. If the person cannot understand (and/or use and weigh) the fact that there is a mismatch between what they say and what they do when required to act, it can be said that they lack capacity to make the decision in question. However, this conclusion can only properly be reached when there is clear evidence of repeated mismatch between what the person says and what they do. This means that in practice it is unlikely to be possible to conclude that the person lacks capacity as a result of their impairment on the basis of one single assessment.

Question: When do we need an assessment of need, when do we need to have a Coordinated multi-agency response, when do we need enquiries?

We don’t need enquiries if a person has not been able to self-care, for example due to a disability, but would accept care and support. Every day, social workers complete this kind of assessment and provide care and support plans to meet the need.

It is when a person is not engaging with services that enquiries are required. Agencies need to find out what has happened to that person to neglect themselves and to prevent them from seeking help. Outcomes explored need to include strategies to heal the impact of their negative experiences on their wellbeing and safety. Capacity assessments need to be coordinated.

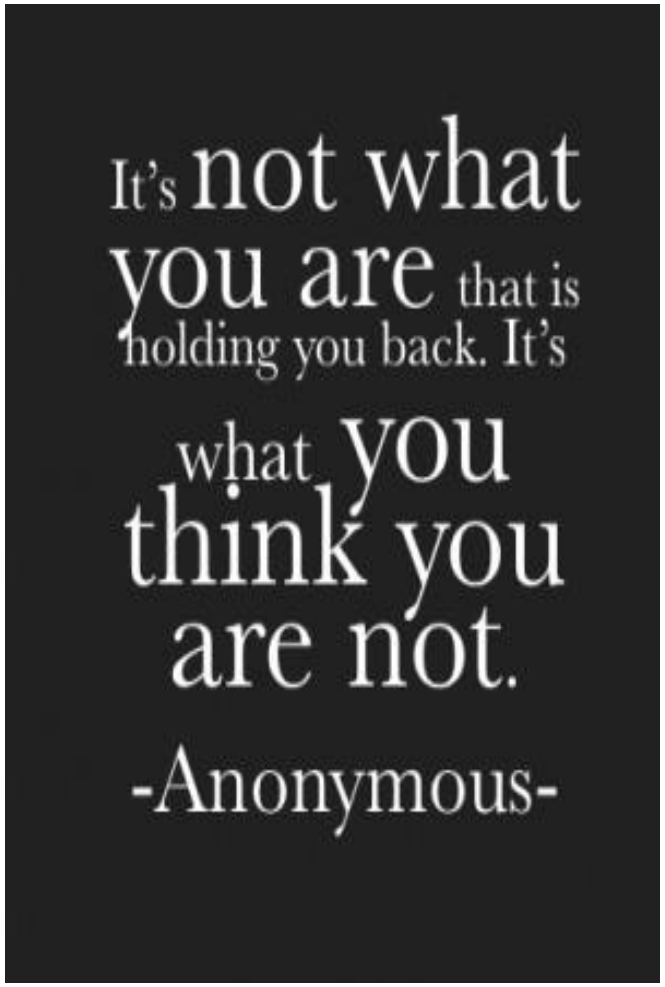
Our self-doubt plus their self-doubt makes solutions impossible



Question: We have no services or resources so what can I do about it? Mental Health say its not for them, it's environmental.

Good old fashioned health and social care work with multi-agency support is what is needed:

- Strength based assessment (See toolkit)
- Build self-esteem, self-confidence and self worth
- Use communication skills
- Link the person with their passions and interests and build
- Link the person with people
- Ensure that they get positive feedback for their contribution to society
- Make the person feel that they are worth healing, being cared for and deserve to feel safe and well



What works

- Be aware of people's experiences of injustice, inequality and threat. Address
- Care Management wont work – allocated worker with MDT support
- The person is eligible for care and support – accept referrals
- Find healing relationships
- Capacity assess – compulsions (Hoarding Disorder) and complex trauma (Executive functioning)
- Provide opportunity for positive feedback
- Explore how power is used against the person in services and seek to empower rather than re-traumatise.
- Connectedness and collective action across organisations and agencies. Don't let the person down again, they will be expecting it and looking for it!
- Challenge disempowering practice or abuse.
- Learn, train and develop together, progress co-production and peer support.
- Foster collaborative research
- Share innovative and good practice
- Meaningful supervision, mentoring, support
- Openness and reflective awareness

What happens if we do not address trauma as part of safeguarding children and adults?

More than eight in 10 men in prison suffered childhood adversity – new report

by Bangor University

Increased crime and prisons full of vulnerable people

How Trauma And Homelessness Are Linked

KERA | By Christopher Connelly

Published March 28, 2019 at 1:23 PM CDT

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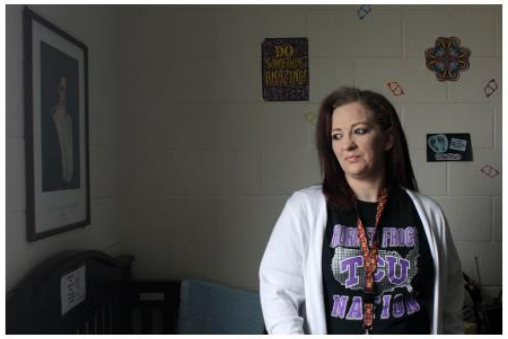

Ashley Franks lives with her son, Cashton, at the Union Gospel Mission in Fort Worth.

An increase of vulnerable people existing on the streets

Epub 2021 Oct 20.

Interpersonal attachment, early family environment, and trauma in hoarding: A systematic review

Kerryne Chia [1], Dave S Pasalich [2], Daniel B Fassnacht [3], Kathina Ali [3], Michael Kyrios [3], Bronte Maclean [2], Jessica R Grisham [4]

An increase in people hoarding and self-neglecting

Home > What is Child Trauma? > Populations at Risk > Trauma and Substance Abuse

ABOUT CHILD TRAUMA

There is a strong connection between traumatic stress and substance abuse that has implications for children and families, whether the user is an adolescent or a parent or caregiver.

An increase of people misusing substances

Additionally, individuals who experience other types of traumas, such as being victims of violence or abuse, are also **more likely to develop mental health problems** when faced with negative experiences.

Trauma and Adverse Childhood Experiences (ACEs) | ECLKC

eclkc.ohs.acf.hhs.gov/publication/trauma-adverse-childhood-experiences-aces

An increase in mental ill health