Trauma Informed Care

For persons with intellectual and/or developmental disabilities

Ruth Myers MD

So I am pretty old

- My specialty as a physician (just a little over 30 years) is persons with IDD who have aggression, self-injury, and/or failure to thrive that severe, long term, and treatment resistant.
- First unpaid job with persons with IDD…at age 13…
- Other DSP jobs-classrooms, group homes…
- First job that made me think a lot more about what we can do besides overpower people

The consultations

That made me want to discover alternatives to restraints

And made me want to question all the coercion-based assumptions

Edward

Age 23

Edward (part 2)

- Found by police chained in a dog kennel
- Next to the corpse of one of the perpetrators
- Covered with feces and infected burns, cuts, and sores
- Starving
- Kicks out at almost anyone who comes near him
- Also tortured by a female physician

How can we help?

What kinds of DSPs

Are most successful with individuals who have aggression, self injury, and/or failure to thrive that is severe, long term, treatment resistant?

What helps people recover?

- Someone who believes in me-optimism and hope
- A nice safe place to live
- Something interesting and fulfilling to do with my day
- Emphasis on my strengths
- Respect for my opinion
- Friends and (supportive) family
- Individualized treatment-whole person approaches
- Trauma informed

What does “trauma informed care” mean?

- Changes the QUESTION from “What bad thing did you do?” to “What happened to you?”
- Comfort vs control
- Speculates that nearly everyone with IDD who has been “in services” has been subjected to excessive toxic stress or overt trauma
- Replaces coercion with healing and recovery
- And no one gets hurt

That is why we created Extraordinary blocking

- Changes the TASK from

"Make it stop"

To

"Make it safe"

And learn

why

The most difficult tasks

Remaining in the compassionate head space when…

- you believe a person can control their aggressive and self-injurious activity AND CHOOSES NOT TO DO SO
- The person lies, cheats, or steals
- The person splits-tells varying stories to separate people on the team
- Stay positive about a person who gets their needs met by manipulation

Even though the surface activity looks like something the person can control, the underlying reasons are not in the person's control

For people to always cooperate and tell the truth…

- They must trust the other person
- Unfortunately, we are part of a system that has not always been trustworthy
- It takes many years to earn that degree of trust
- Dishonest but harmless means of getting needs met are better than violence

So what are examples of unhelpful systems responses?

- The participant was found wandering the streets after seeing his brother suicide by gunshot wound to the head. The home was filled with trash and the man had been placed involuntarily on a starvation diet and lost 250
- A foster father was filmed in the act of raping the participant
- The participant was starved for the first several years of her life, was raped by a family member, and used as a prostitute at a children's residential facility.
- A psychiatric facility manipulated the system so that a mentally ill participant ended up in prison and now has a record

Phillis

About 45 years old; years ago had been referred for “interfering with staff,’ and now an old problem with stealing is getting worse

Effects of unresolved trauma and/or unremitting toxic stress

- Premature death
- Increased rate of pulmonary diseases
- Accelerated cardiovascular disease
- Impaired immune function
- Increased rates of autoimmune disorders
- Increased rates of diabetes
- Increased cancer rates
- Functioning far below capabilities
- Altered physical/sexual development
- Suicide
- Eating disorders
- Addictions
- Liver disease
- Chronic pain/complex pain syndromes
- PTSD
- Treatment resistance of all other health problems
- So-called personality disorders

Workplace Effects of failure to address unresolved trauma and/or unremitting toxic stress

- Higher turnover
- Increased workers' compensation costs
- Absenteeism
- Increased injuries to participants and staff
- Preventable deaths
- Work performance below capabilities
- Higher rates of burnout and hostility

First evidence-based article about effects of implementation of trauma informed care in services that serve traditionally hard to serve individuals:

- Ryan RM, Use of coercive practices with persons with developmental disabilities. In Pollack DA. Moving from Coercion to Collaboration in Mental Health Services. DHHS Publication no (SMA) 04-3869. Rockville, MD: Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, 2004

Trauma and persons with IDD

- Usually abuse by persons in a position of trust; gender stereotypes do not apply
- 87% in our recent data
- 100% in some samples
- The lowest percentage in any study that asks is 66%
- Any history of severe neglect eventually was found to have been accompanied by abuse
- First evidence-based article on treatment of PTSD and persons with IDD: *Ryan RM, Posttraumatic Stress Disorder in Persons With Developmental Disabilities. Community Mental Health Journal Vol 30, no 1, 45-54, 1994*

Community Mental Health Journal, Vol. 37, No. 6, December 2001

Physician Unwitting Participation in Abuse and Neglect of Persons with Developmental Disabilities

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ABSTRACT: The vast majority of birth parents and foster parents for children with special needs do the best they can in challenging circumstances. Many describe the frustrating circumstance of knowing more than their physicians about their child's unusual medical conditions. In general, physicians are well-advised to listen carefully to the reports of observant, caring parents and foster parents, and to give these observations at least as much weight as their own. However, in the work of our traveling clinic we have observed a number of situations of abuse and neglect which were perpetrated by parents or foster parents, and where the actual acts of abuse and/or neglect were wholly or in part endorsed, in writing, by the treating physician.

KEY WORDS: abuse; neglect; developmental disabilities; mental retardation; house calls.

BACKGROUND OF CLINIC

The consultation clinic which saw most of the individuals described here is a traveling transdisciplinary team designed to consult for persons with developmental disabilities and complex needs and the teams which support them. The service is offered free of charge to persons throughout

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What do the studies say is the biggest obstacle to addressing trauma?

For people with IDD there are two major and consistent obstacles:

1. Asking the question
2. Realizing it matters

Really Smart and helpful experts:

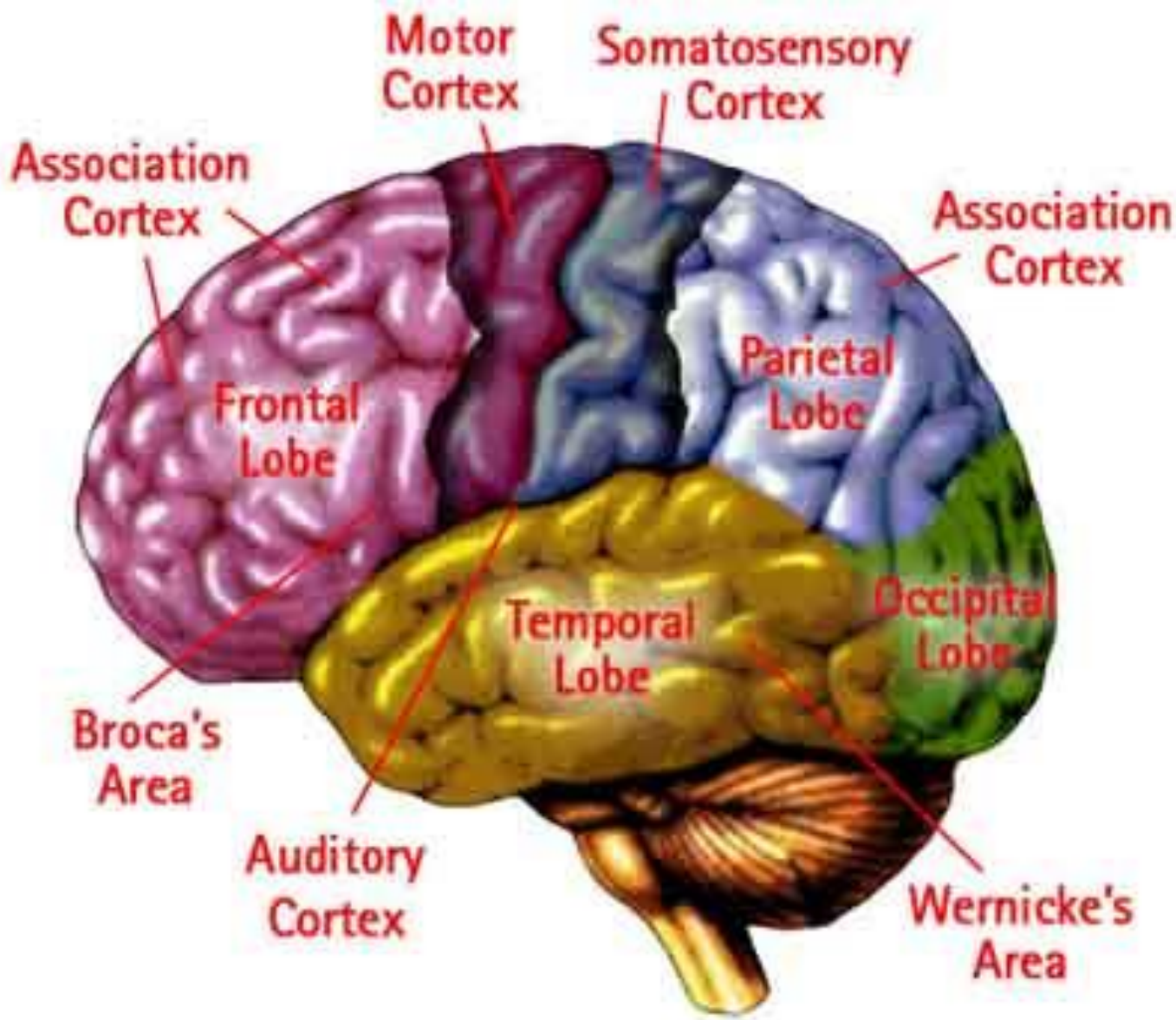
- Nora Baladerian
- Julie Gentile
- Dorothy Griffiths
- Dave Hingburger
- Sheila Hollins
- David Pitonyak
- Richard Sobsey

What are the differences

Between good stress,

excessive potentially toxic stress,

and trauma?


Motor Cortex
Somatosensory Cortex
Association Cortex
Association Cortex
Parietal Lobe
Frontal Lobe
Temporal Lobe
Occipital Lobe
Broca's Area
Auditory Cortex
Wernicke's Area

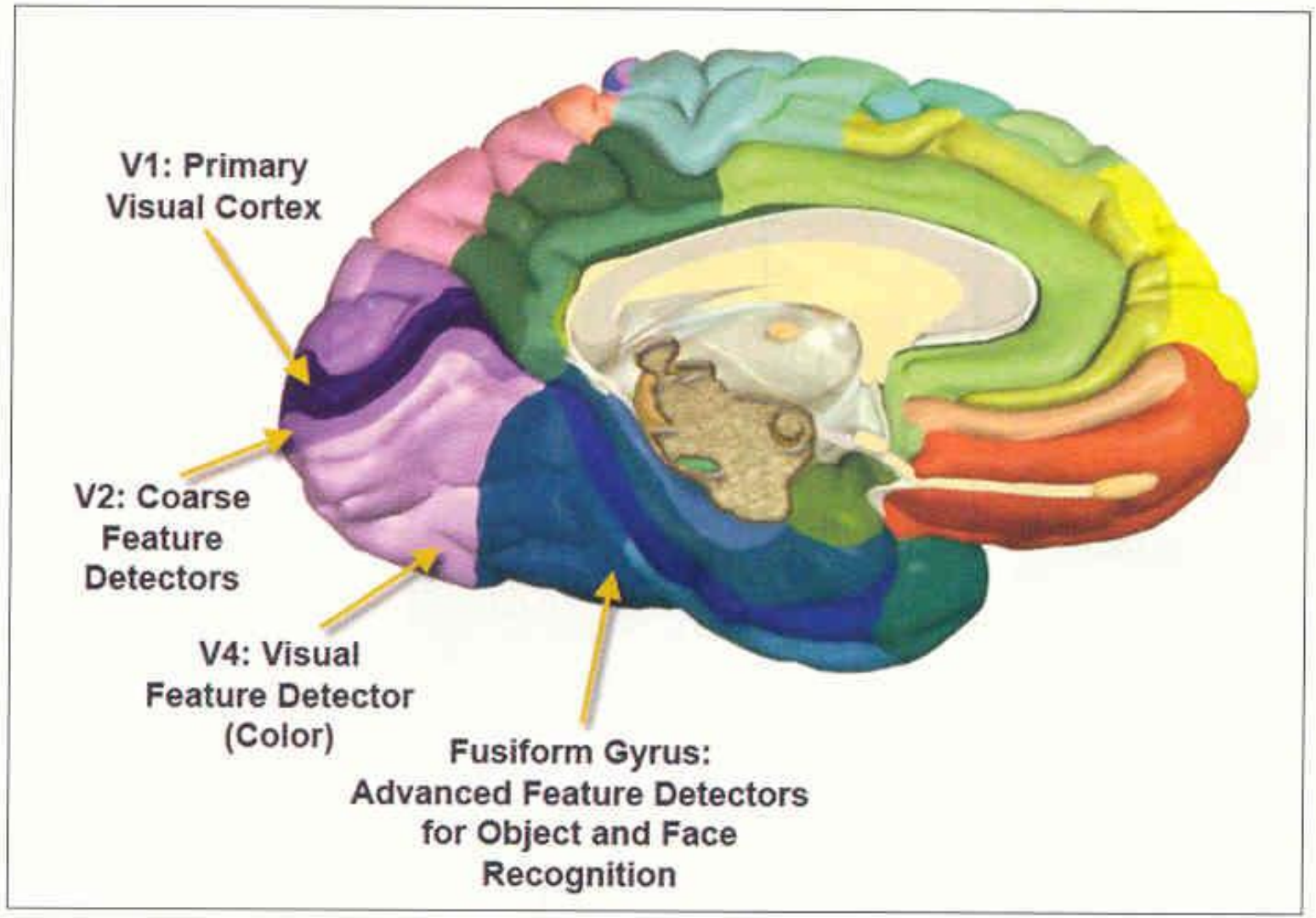


Figure 2. The visual cortices. Visual information is internalized and projected onto the primary visual cortex (V1). From here, data flow to the various feature detectors of the unimodal visual cortex (such as V2 and V4), and then to the heteromodal cortex of the fusiform gyrus, where identification of the visually perceived object takes place. Colored boundaries define specific Brodmann areas. (Brain image copyright 3B Scientific GmbH 2001. Excerpted from NEUROteacher™. Used with permission.)

Good Stress

- lights up your prefrontal executive and attention brain parts with just the right amount of adrenalins
- Improved short term memory
- Attention to detail
- Problem solving/planning with future goals in mind
- Emotional regulation
- Sociability/ability to understand others

Examples

- This is the sort of stress over which a person can exert some control- the stresses we choose
- Competitive sports or challenging individual sports
- Challenging course of study
- Major family events such as weddings

Excessive or “bad” stress

- Shuts down the prefrontal brain parts; lights up the limbic parts when the brain is drowned in way too much adrenalin
- Forgetfulness, feels like brain goes blank
- Reduced concentration and focus
- Increase distractibility
- Disorganized impulsive behavior based on perceived immediate needs

More possible results- excessive or “bad” stress

- Narrowed or rigid thinking
- Tunnel vision
- Perseverative thinking
- Increased craving and habits
- Heightened moodiness
- Social withdrawal
- Learned helplessness

Examples (part 2)

- A rotten and/or boring job that the person did not want and is not permitted to leave
- Living with someone the person dislikes or is scared of, and not permitted to leave
- Constant exposure to bigotry/disphobia
- Health care access discrimination; delayed care
- COVID 19 pandemic precautions
- Abrasive/ demeaning/ incompetent support staff
- Lousy nutrition or nasty food- no opportunities to choose other foods

More examples:

- Lack of choice
- Gratuitous criticism (often disguised as guidance)
- External and ongoing suppression of self expression (sexual, religious, friendship, entertainment)
- Receiving blame or “programming” for symptoms the person cannot control

How do we reverse the effects of potentially toxic stress?

Restoring peace

Restorative activities not all apply to every person

- Mutual loving relationships where contact is possible just about any time
- A nice place to live; home of one's own
- Daytime activities the person likes
- Sex with a partner
- Happy marriage
- Children
- Taking days off work when not really sick
- Entertainment the person chooses
- Vices, in moderation (alcohol, tobacco, weed, junk food, and so on)
- Spiritual practices the person chooses
- Athletics that the person likes
- Self-advocacy activities
- Individualized self-expression
- Time alone with no one telling the person what to do

What do you notice about this list

Of restorative activities?

Examples (part 3)

- Cuppa coffee and a cigarette
- Half a glass of white wine
- Donuts… lots and lots of donuts
- At least eight cups of strong black coffee per day
- I want fried potatoes with cheese
- Watching The Wizard of Oz… every day for years…

Trauma

- Experience which is not in the realm of ordinary life experience and is frightening, painful, and/or entails a risk of death
- Natural disasters (Katrina)- especially worse if those who are supposed to help do not
- Rape
- Head injury (any cause)
- Fire
- Serious burns (any cause)

Trauma (part 2)

- Nonsexual physical assault
- Witnessing rape, assault, murder, or attempted murder (worse if perpetrator is supposed to be a person in position of authority or trust, such as a parent, priest, police officer, sibling, staff…)
- Serious motor vehicle accident
- Poor quality, incomplete, or abusive medical care

Principles of trauma-informed care (and persons with IDD):

- Almost everyone with IDD who receives services has experienced toxic stress or trauma
- Toxic stress and trauma affect persons with IDD the same way they affect everyone else
- No one gets hurt
- A culture of trauma informed care produces measurable benefits for individuals who receive services **and individuals who provide services**
- The idea that it is best for DSPs to be neutral, distant, and detached is wrong
- A distant, controlling approach to persons magnifies the effects of toxic stress and trauma

Principles of trauma-informed care (and persons with IDD): continued

- Nothing about me without me; every decision that affects the individual should incorporate the individual's opinion
- Ask more questions, stop giving orders
- No one gets hired unless the participant interviews and approves them
- Participants can fire DSPs any time and do not have to give a reason
- Encourage the participant to create the sensory environment; what sounds, smells, light levels, decorations, and so on work well for that person?

Trauma informed care is more effective than control-based cares

It is also a very hard shift for people who like to be able to intimidate people into compliance

Some who have provided primarily control and coercion-based programs

Are unable to adjust… these programs hurt people and produce unnecessary stress on the whole system of care-they must change or close

But Ruth, is it really possible that I could know a person for years and not know about a trauma history?

(Yes)

Potential errors in trauma informed care

- Pressure
- Projection
- Pity
- Premature conclusions

A certain percentage of persons exposed to trauma

Develop full-syndrome posttraumatic stress disorder (PTSD)

Does everyone exposed to trauma develop PTSD?

No, there are many possible outcomes, including many health problems, which means we need excellent medical care to get the complications identified and treated

Other influences:

- Genetics (family)- do people in this person's family tend to get ulcers, cancer, panic disorder, migraines, depression…?
- Genetics (personal)- does this person have a genetic/ metabolic syndrome which adds more medical stress?

The functions of the brain are changed by trauma and/or chronic unresolved bad stress

Development is altered

Essentially

Trauma and/or chronic unresolved bad stress change the structures and chemicals in the brain in a way that trains the person to have a full on catastrophic-freeze, flight, or fight- reaction to every little challenge

Results of trauma recovery/resolved toxic stress

- Good nonpsychiatric physical health; good self management of ongoing medical problems
- Adaptive behavior control
- Regulated hedonic drives
- Minimal use of intoxicants, junk food
- Proportional responses to stress

Isn’t it true that people who have been abused…

Go on to abuse others?

NOT NECESSARILY

- Perpetrators might or might not have been abused
- Most abuse survivors do NOT go on to hurt anyone else

Clues to possible abuse

- Early hysterectomy or tubal ligation, especially in a child
- Unexplained scars, genital repairs, or bony distortions
- Frequent UTI’s
- Cervical inflammation on Pap, venereal infections
- Hepatitis B or C
- Rectal digging or prolapse
- Rectal deformity
- Abuse of siblings
- Self-injurious masturbation
- Repetition phenomena
- Explicit efforts to provoke staff/friends
- Self mutilation

Other places to get information

- Other people who lived in the same place
- Staff who worked there
- Neighbors
- Follow the money (qualifying reports)
- Teachers’ notes
- Police reports
- Old disappeared reports (B&E)

Treatment works

It is not easy, but it works

latrogenic =

Harm caused by treatment

Eliminate latrogenic factors

- Stupid rules
- Incompetent or rude health care providers
- Contact with perpetrators
- Humiliating, boring or coercive behavior plans
- Unwanted housemates
- Unnecessary medications
- Irrelevant treatment goals- I call these “because we can” goals-bed making, setting the table, folding clothes a certain way…

Other examples of iatrogenic factors

- Anything that involves treating an adult like a child. We must eliminate forever the words “use your napkin” and “you can’t go out until you make your bed.”
- The only possible response to a really loud burp or fart is “good one.”
- Discard any gratuitous rituals the person does not like or want-like setting the table, eating whatever is offered, wearing clothes the DSP thinks are more appropriate, and so on
- And we must not ever tell adults they cannot curse
- Obviously coercion is contraindicated

Feelings States which interfere with recovery and growth (UNLESS the person chooses any of this as part of working toward some desirable goal)

- Hunger
- Intense anger
- Intense fear
- Excessive stress
- Fatigue
- Pain
- Intense Anxiety

Examples of time and energy wasters

- Requiring the person to act like they like someone they dislike
- Compliance with schedule created by someone else or for someone else
- Reprimanding profanity
- Clothing and makeup standards imposed by someone else
- Getting the person to act like they like a situation they dislike
- Enforcing medical orders the person understands and does not want to follow
- Deciding when a person should alter unhealthy habits

Examples of other factors that interfere with recovery and growth:

- Counseling people to be compliant with unacceptable living situations or abuse
- Telling people to be obedient to anyone who gives them orders
- Restraint
- Criticism (even when it is called “guidance,” the person’s brain knows what it is)

Insisting that DSPs do these things also harms the DSPs

Which is/are the helpful response(s) to someone who is hitting people?

- Stop doing that
- Your behavior is upsetting other people
- How do you feel when you punch people? Is that working well for you?
- You should stop doing that
- You really need to stop doing that
- I really want you to quit that
- What’s going on?
- Can I help?
- Ouch… looks like you are seriously pissed (or scared or whatever)

It is essential to avoid using the person's time and energy

To change things which do not need to be fixed

We might also need to

Help reverse the damage caused by previous interventions

Unfortunately, many may have endured problematic staff or family responses when they were abused:

- Blaming (sex education for a rape victim says if you weren't so stupid this would not have happened)
- Mutilation (sterilization)
- Restriction (you won't be allowed to go out anymore)
- Restraint (often chemical)
- Other forms of punishment (reprimands for expression of anger and rage, restriction of access to comforting vices)

In day to day interactions

- People with IDD who survive to adulthood are stronger than the average person
- Those who passively sit back and accept everything that is done to them typically have very short life spans
- A continuous state of fight or flight is very likely the reason the person is still alive

More day to day ideas

- It can take weeks or years for the person to end the testing
- Each time there is a major life change, testing might resume
- When people are first learning to claim and use their power, they usually make mistakes
- How we respond to those mistakes makes a big difference
- The person is unconsciously or consciously asking questions about you
- Here are some questions to be aware of…

Are you going to hurt me?

When you get angry…or just because you like it?

Are you loyal?

Or will you make excuses for abusers?

Or will you stick by me no matter how I look in public?

Are you on a power trip?

Are you going to try to overpower me?

Do you really mean it when you talk about

Choice-making

Sexuality

Looking however I want to look in public

Do you lie or pretend?

That you are more committed to me than you really are?

Do you experience remorse?

Do you admit mistakes and try to make it right?

Feelings states which are neutral and stall recovery and growth

- Indifference
- Boredom

Let’s minimize this stuff

Feelings states which facilitate recovery and growth

- Excitement (positive)
- Mild positive stress
- Passion
- Affection
- Amusement
- Multisensory involvement
- Accurate mirroring

Let’s increase this stuff

Habilitative changes and DSP training and support

- Elimination of DSP cliques-they tend to be nasty and create a toxic work environment
- Opportunities to process together-trauma revelations, effective support strategies, novel ideas, and nontoxic correction of mistakes
- Culture of good health for everyone in the system
- Zero tolerance for abuse or neglect
- Frequent celebrations of successes

Actions for today

- Pull out the BSP and schedule
- Next to each item, write down who decided this was a rule or goal
- Eliminate any goals that would not apply to any other adult
- Ask the participant if they agree with the other rules or goals
- Ask the participant if they would like to change this rule or goal
- Change whatever rules or goals the participant wants to change
- See how it works out
- If/when it doesn’t work out, collaborate with the person to create a mutually acceptable alternative

Idiosyncratic useful responses

- Look at past “inappropriate” behaviors
- Think of the actual traumas and what might respond to them
- Of course always continue to consult with the individual and the people who know the person well
- Honor all harmless customs and preferences

And with regard to Edward

How shall we proceed?

Trauma Informed Care-summary

- As compared to neutral care and coercion-based care, trauma informed care produces better quality of life and function for participants with IDD
- It also produces improved staff retention and reduces workers' compensation claims and absenteeism
- Change the QUESTION from "What bad thing did you do?" to "What happened to you?"
- Changes the TASK from "Make it stop" to "Make it safe"… and learn **why**
- If implemented properly, no one gets hurt
- And everyone has a lot more fun