



# Non-behavioural approaches to supporting people with intellectual disabilities

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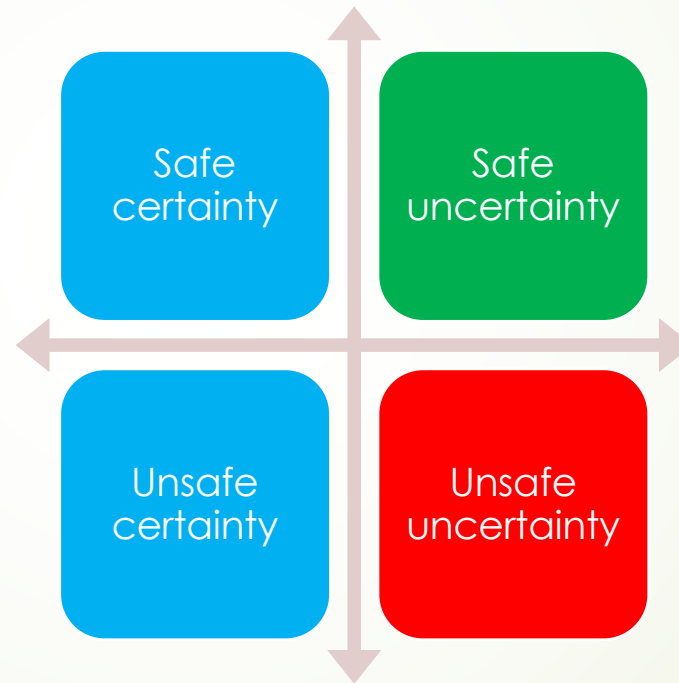
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# Plan

- 10
  - Tuning in to emotions rather than behaviour
  - The Scale of Emotional Development - S (short)
- 11.15 – coffee
- 11.30 – Attachment
  - Introduction & update
  - Video
  - Safe Base Safe Haven Observation Scale
- 1 - lunch
- 2 – Supporting damaged people whose emotions are dysregulated
  - Disorganised attachments
  - Trauma-Informed Care
    - What it is
    - what TiC lost when it entered ID - and what that tells us
- 3.15 - Making claims that matter

# Towards a position of safe uncertainty





# Communications that create safe uncertainty

## Helpful

- Openness to the new: curiosity
- Conscientiousness
- Extraversion
- Intelligence
- Amiability

## The 4 horsemen of the apocalypse

- Criticism
- Defensiveness
- Contempt
- Stonewalling

What don't you want to change?  
Put it in a safe place





# Assumptions

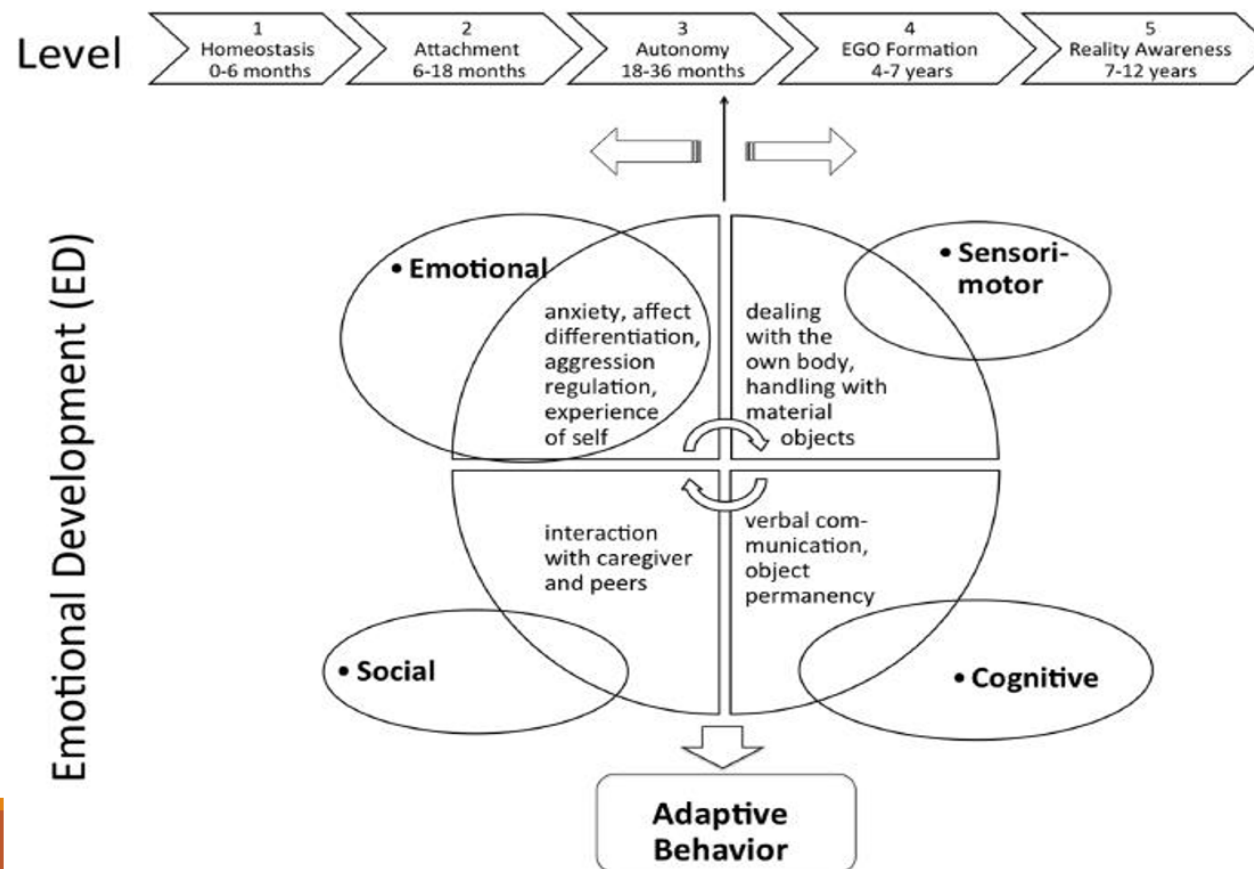
- Discrepancy between cognitive & emotional development in ID
- Over-estimation & too high expectations significant factor in challenges
- Priority: meeting basic emotional needs first
- So: need to appraise emotional development

# Five-stage model for emotional development

(quoted from Došen, 2007, p. 69)

Stage 1 0-6 mo	Stage 2 6-18 mo	Stage 3 18 mo-3y	Stage 4 3-7y	Stage 5 7-12y
Adaptation	First Socialization	Individuation	Identification	Reality Awareness
“regulation of physiological needs, integration of sensory input, structuring of space, time and persons, and social Interaction”	“bodily contact, attachment person, social stimulation and handling of material objects”	“certain distance in contact, confirmation of autonomy, and reward of social behaviour”	“identification with important others, social acceptance and support, and social competence”	“cognitive competence, physical competence, friendship, creativity, productivity and ‘golden rules’ of social behaviour”

# Sappok et al. (2013, p. 3): domains of ED







# Asking the right questions

- (What is the problem with this person?)
- Who is this person?
- How does this person affect me?
- What are his/her emotional needs?
- How can our service better attune to these basic emotional needs?
- What is my programme with you (not/not only 'what is your programme?')
- What do I/the team need to attune support and keep it up?



# Sappok et al 2016 SED-S

8 groups each discuss 1 of the domains of emotional development

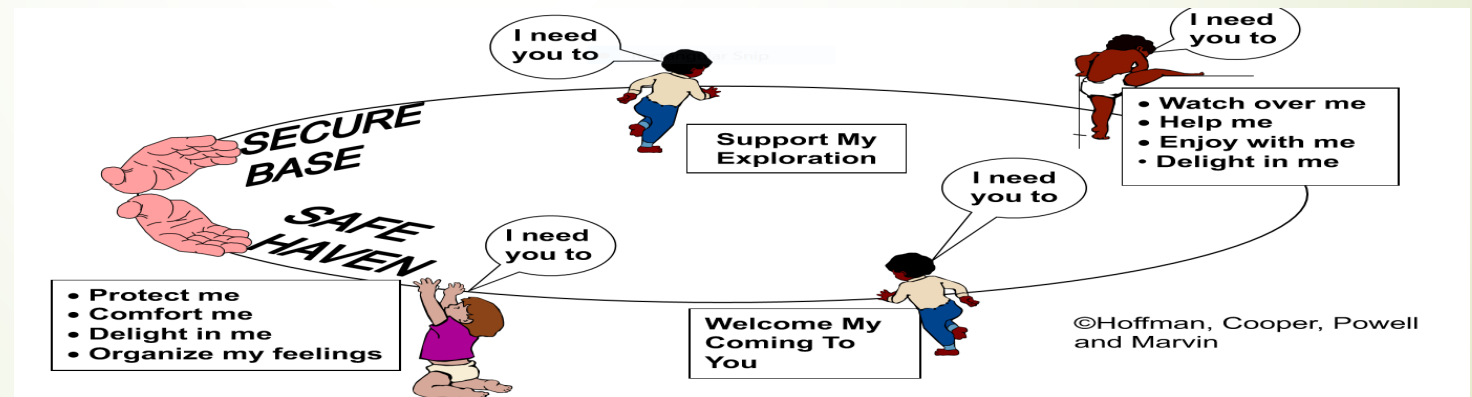
## Stage 1: psychophysiological homeostasis 0-6m/Profound ID

- Type of support: homeostasis - dysregulation
  - Easily disrupted
  - Very sensory & highly sensitive
  - Floating on internal tension barometer
- Caregiver job to co-regulate by:
  - Proximity
  - Low stimulus environment
  - Structure
  - rest



## Stage 2: Attachment 6-18 months/profound ID

- Type of support needs: trust – suspicion
  - Wanting, searching, following: 'attention-seeking'
  - Unsafe – afraid to be alone
  - Needs emotional refuelling
- Caregiver job: Safety – near from a distance, boundaries



## Stage 3: Individuation 18m-3y/Severe ID

- Start of self (boy-girl)
- Me, me, me
- No, no, no
- Caregiver job: Communicate to balance autonomy-dependence
  - Support from a distance
  - Discrete guidance - rules and consequences
  - Shared responsibility
  - Shared pride in achievement



## Stage 4: Identification 3-7y/severe-moderate ID

- Balance initiative-taking & fear of failure
- Choices – what & who do I like/want?
- Learning social norms & values
- Identify with important others footballers, popstars
- Caregiver job: invite, stimulate, build trust



## Stage 5: Reality awareness 7-12/mild – borderline ID

- Support need for relationships
  - Working on self-confidence – inferiority
  - Understanding role & place in environment
- Caregiver job:
  - build individual and group social skills
  - Re-interpret events that were experienced negatively





# Remember the assumptions

- Assessment only useful when it informs support
- Not changing clients or giving prescriptions
- About starting a process:
  - what sort of Qs are relevant to this person
  - how can we meet his/her needs
  - How can I/we change to help person develop
- Supervision does not tell but asks refreshing questions:
  - What emotions does X provoke in you? In your team?
  - When does it go better with X?
  - If X did not have an ID what job or profession would he/she have had?





## **It is about making people stronger**

Search for an entrance in small cracks

Not overwhelming with expertise

Giving little ideas

Helping caregivers to build emotional development into daily life





## Schuengel's paradox

- For children with ID ...attachment relationships may be even more important for healthy socioemotional development ... while [their] chances of experiencing secure, organized attachment appear in fact to be lower.... ID, unfortunately, is a field in which symptoms of disorders of attachment occur in relatively high frequency (2013:43)



## Attachment types

For detailed understanding:

Main, M. (2000) The organized categories of infant child and adult attachment: flexible vs inflexible attention under attachment-related stress. J American Psychoanalytic Association, 48 (4): 1055-1096.

Hesse, E. & Main, M. (2000). Disorganized infant, child and adult attachment. J American Psychoanalytic Association, 48 (4): 1097-1127

Child attachment to key figure	Adult state of mind about relationships
<i>Secure</i>	<i>Autonomous</i>
<i>Ambivalent</i>	<i>Preoccupied</i>
<i>Avoidant</i>	<i>Dismissing</i>
<i>Disorganised</i>	<i>Unresolved</i>



# Marielle

Marielle is 9 yrs, developmental age of about 18 months, blind, some physical difficulties. Being left alone elicits protest: self-injury, screaming, unpredictability, attacking people, and disturbed sleep.

Video portrays therapy to address insecure (anxious-ambivalent) attachment: organised, stable and has survival value. Her protest is not Disorganised.

Things to watch out for:

- Marielle's body language early and later. What changed? Why?
- The attachment therapy addresses one key issue related to Marielle's emotional development. What is it?
- At the end a staff member describes having learned to 'keep an open line'. What do you think that means? How could you promote that in any services you have experienced?



## More ways to tune in to attachment

- Safe Base Safe Haven Observation Scale  
– de Schipper & Schuengel
- Behavioural signs of disturbed attachment
- Caregiver Helplessness Scale
- Adult Attachment Picture Projective System (AAPPS)



**Apply knowledge of attachment to improve relationships between the person with ID, care staff & family**



# Disorganised attachment

- Differs from insecure but organised attachments: Preoccupied, Dismissing
- Primary attachment relationship contains 'terror without resolution'
- Radically compromises psychobiological, social and emotional development
- Strong association with adult unstable & borderline personality disorders



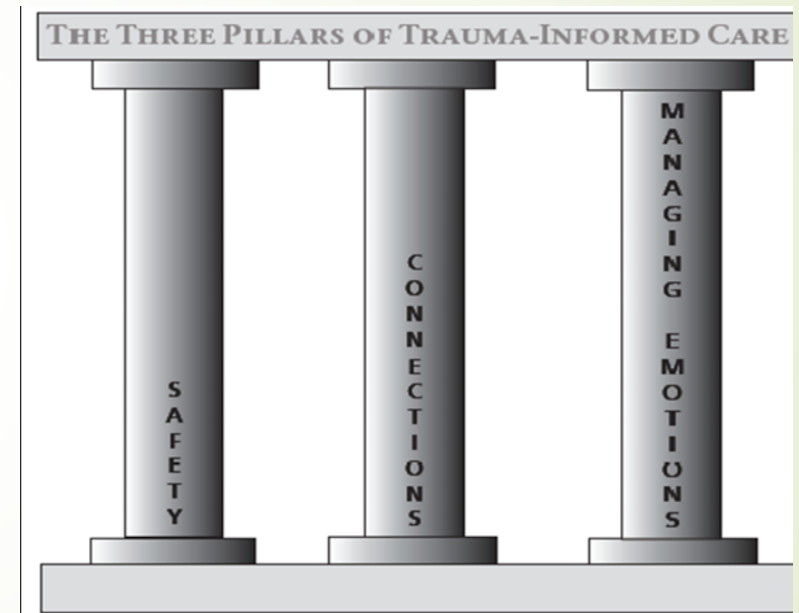
# So, what is key to TiC?

Keesler (2014) TiC in ID:

5 TIC principles to foster a common language and minimise the risk of re-traumatisation

- Safety
- Trustworthiness
- Choice
- Collaboration
- Empowerment

But Bath 2008 3 pillars differ:





# A Theory of Everything

Gardiner, Iarocci & Moretti, (2017).  
Integrative care for adolescents with dual  
diagnosis: Considering trauma and  
attachment within an innovative model for  
clinical practice. J Mental Health Research in  
ID, DOI: 10.1080/19315864.2017.1337835

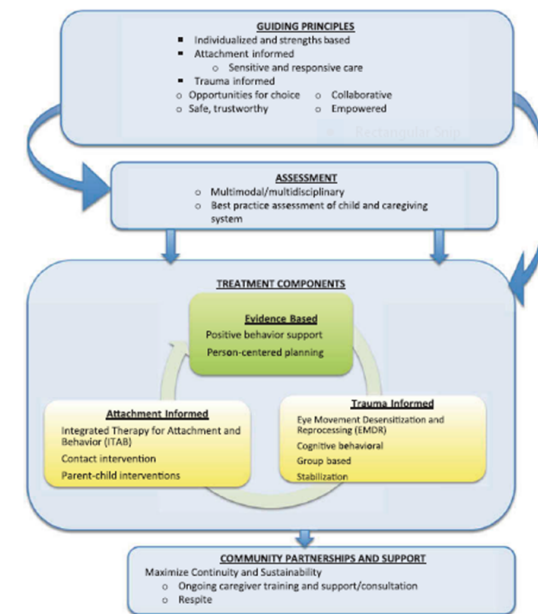


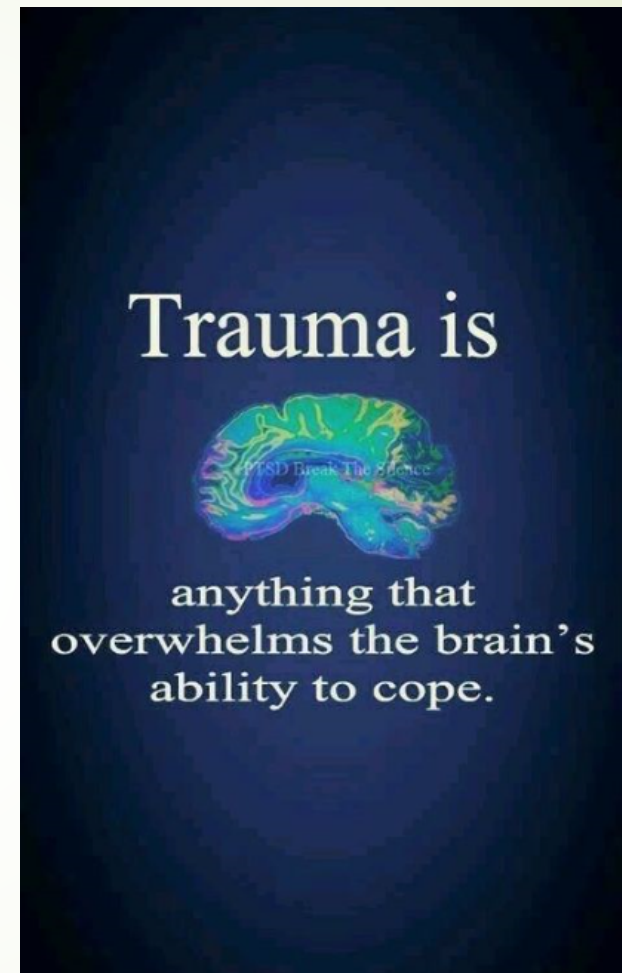
Figure 1. Innovative treatment and incorporating evidence-based and emerging approaches.


## Trauma-informed care

"The core problems of affect dysregulation, structural dissociation, somatic dysregulation, impaired self-development and disorganised attachment are likely to remain the foundation for clinicians working with survivors of complex trauma, regardless of the specific diagnosis or assessment and treatment methodologies in use."

Kezelman & Stavropoulos (2012:3)

<https://www.blueknot.org.au/resources/Publications/Practice-Guidelines>





# Trauma-Informed

## Your ability to connect is your best therapeutic tool

- Changes to a trauma-informed organizational service system environment will be experienced by all involved as **a profound cultural shift** :
  - consumers and their conditions and behaviours are viewed differently
  - staff respond differently
  - the day-to-day delivery of services is conducted differently-ongoing attention to well-being, boundaries, supervision

# Window of Tolerance

## Hyperarousal Zone

Increased sensation  
Emotional reactivity  
Hypervigilance  
Intrusive imagery  
Disorganised cognitive processing



Window of Tolerance  
Optimal Arousal Zone



## Hypoarousal Zone

Relative absence of sensation  
Numbing of emotions  
Disabled cognitive processing  
Reduced physical movement

The three zones of arousal: A simple model for understanding the regulation of autonomic arousal (Ogden, Minton & Pain, *Trauma and the Body*, p. 27)



# Trauma-informed Practice

- Co-regulate chaotic emotions (nurses use 'high observations') to stay within the window of tolerance
- Attitude shift from 'what's wrong with you?' to 'what happened to you?'
  - distinguish single event PTSD from complex/multiple trauma
  - but avoid service demand to rehearse history: be clear who is leading the assessment
- Incorporate a message of optimism and hope into all interactions: most people (MH) recover from trauma
- **A program cannot be safe for clients unless it is simultaneously safe for staff.** Staff should be educated in trauma sensitivity, & should receive regular (*at least monthly*) professional supervision
- <https://www.blueknot.org.au/resources/Publications/Practice-Guidelines>



# Help me! But I won't let you!

- Fiona's story
- Use the 5 stages of emotional development to estimate where she might be on that
- Draw on that to imagine what sort of relationship she needs from staff
- Identify things the team of staff need to think about in supporting her



# Attuning to dissociation

## **The escape when there is no escape**

- Spaces out easily
- Loses coherency when speaking about childhood events
- Can't remember much of childhood years
- Abruptly switches from calm discussion to a hostile, terrified, shut-down, or disorganised state
- Shows inappropriate affect when discussing distressing events
- Speaks in the third person about the self
- Changes in voice tone and pitch





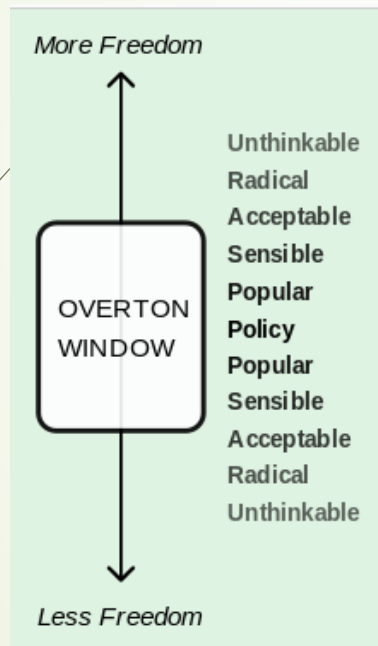
# Psychomotor Therapy

Rather than focusing on how people make meaning of their experience – their narrative of the past – the focus is on clients' physical self-experience and self-awareness. When past experience is embodied in present physiological states and actions... The role of the therapist is to facilitate self-awareness and self-regulation, rather than to witness and interpret the trauma.

- Joshua J. Kay, Jennifer A. Clegg, Claudia Emck & Penny J. Standen (2015): The feasibility of psychomotor therapy in acute mental health services for adults with intellectual disability, *Journal of Intellectual and Developmental Disability*, DOI: 10.3109/13668250.2015.1094037
- KU University Leuven English-language courses
- Psymot(ID) assessment, contact Claudia Emck, VU University, Amsterdam



# The window of politically acceptable policies



Policies outside window only supported by

- **True leaders** with rare ability to shift window alone

Or

- **Politicians who risk electoral defeat** perceived irrelevant or out of touch



## Bring attachment inside window of acceptable policies

1. Value its distinctiveness
2. Resist attachment being drawn into PBS
3. Find a way to work with parents:
  - Take into account feminist critique that attachment amplifies mother-blaming
  - And address circumstances that amplify risk of family abuse and neglect
4. Build in service support to staff exposed to preoccupied attachments



# Conclusions

Attachment has much to offer but

- Effortful learning how to see it: train in AAPS
- Struggles for air in neoliberal individualist cultures organised around behavioural approaches
- Dominant ID culture of 'brightsiding' unsympathetic to problems of abuse and distress



## Further advanced reading

- Bath, H. (2017), The trouble with trauma. Scottish Journal of Residential Child Care V.16, No.1.[https://www.celcis.org/files/9014/9519/3320/2017\\_Vol\\_16\\_1\\_Bath\\_H\\_The\\_Trouble\\_with\\_Trauma.pdf](https://www.celcis.org/files/9014/9519/3320/2017_Vol_16_1_Bath_H_The_Trouble_with_Trauma.pdf)
- Cutuli, J. J., Alderfer, M. A., & Marsac, M. L. (2019). Introduction to the special issue: Trauma-informed care for children and families. Psychological Services, 16(1), 1-6. <http://dx.doi.org/10.1037/ser0000330>
- Gallichan, D. & George, C. (2018). The Adult Attachment Projective Picture System: a pilot study of inter-rater reliability and face validity with adults with intellectual disabilities. Advances in Mental Health and Intellectual Disabilities, Vol. 12 Issue: 2, pp.57-66, <https://doi.org/10.1108/AMHID-11-2017-0036>