Applying and Adapting ACT with Adults with Intellectual Disabilities

ACBS World Conference 15

Seville 2017

Welcome!

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The Context

People with Intellectual Disabilities are:

People – with uniquely human potential for joy, greatness and suffering who…….

are often **more likely** than those without ID's to experience **adversities** – physical health difficulties, economic disadvantage, abuse, stigmatisation, bullying, isolation, exclusion……

as likely and sometimes more likely to develop **mental health and emotional difficulties** and more likely to display **behaviours that challenge** throughout the life-course

…….often require **additional support** from other **people** (who also share in the uniquely human potential for joy, greatness and suffering) to learn, develop and maintain independence

Nick Gore

Today's session:

- 3 presentations describing ongoing work to support individuals with IDD and ways to understand and influence the wider support system
- Discussions to support the next steps
- Thank you and enjoy!

Google Group

- After the UK and Ireland Conference in November 2016 a Google group was set up for clinicians to be able to share information and ideas for clinical work or research. Please come and join!

cbs4id@googlegroups.com

Shining a light on the future

Northumberland, Tyne and Wear NHS
NHS Foundation Trust

Lessons learned from working with ACT with adults with Intellectual Disabilities

Dr. Mark Oliver
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Northumberland Community Team for People with Learning Disabilities

ACBS World Conference 15
Seville, Spain. 22nd – 25th June 2017

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I have not received and will not receive any commercial support related to this presentation or the work presented in this presentation.

Overview

- Background to Intellectual Disability
- ID and ACT
- Case examples / Lessons learned

Intellectual Disability

Intellectual Disability goes by different names in different healthcare jurisdictions:

- Mental Retardation
- Learning Disability
- Developmental Disability
- Mental Handicap
- Mental Disability
- Mental Deficiency
- Mental Subnormality

World Health Organization (2007). *Atlas: Global resources for persons with intellectual disabilities.* Geneva, World Health Organization.

Learning Difficulties / Learning Disability

Learning Difficulties (in UK terminology)[1] / Learning Disabilities (US terminology)[2] are terms used in educational settings to describe issues affecting how information is learned and processed:

- Dyslexia
- Dyscalcula
- Dyspraxia
- ADD / ADHD

These problems are independent of people's intellectual ability.

[1] British Dyslexia Association website: www.bdadyslexia.org.uk
[2] The National Center for Learning Disabilities, (2014). The State of Learning Disabilities, 3rd Ed.

ID Criteria

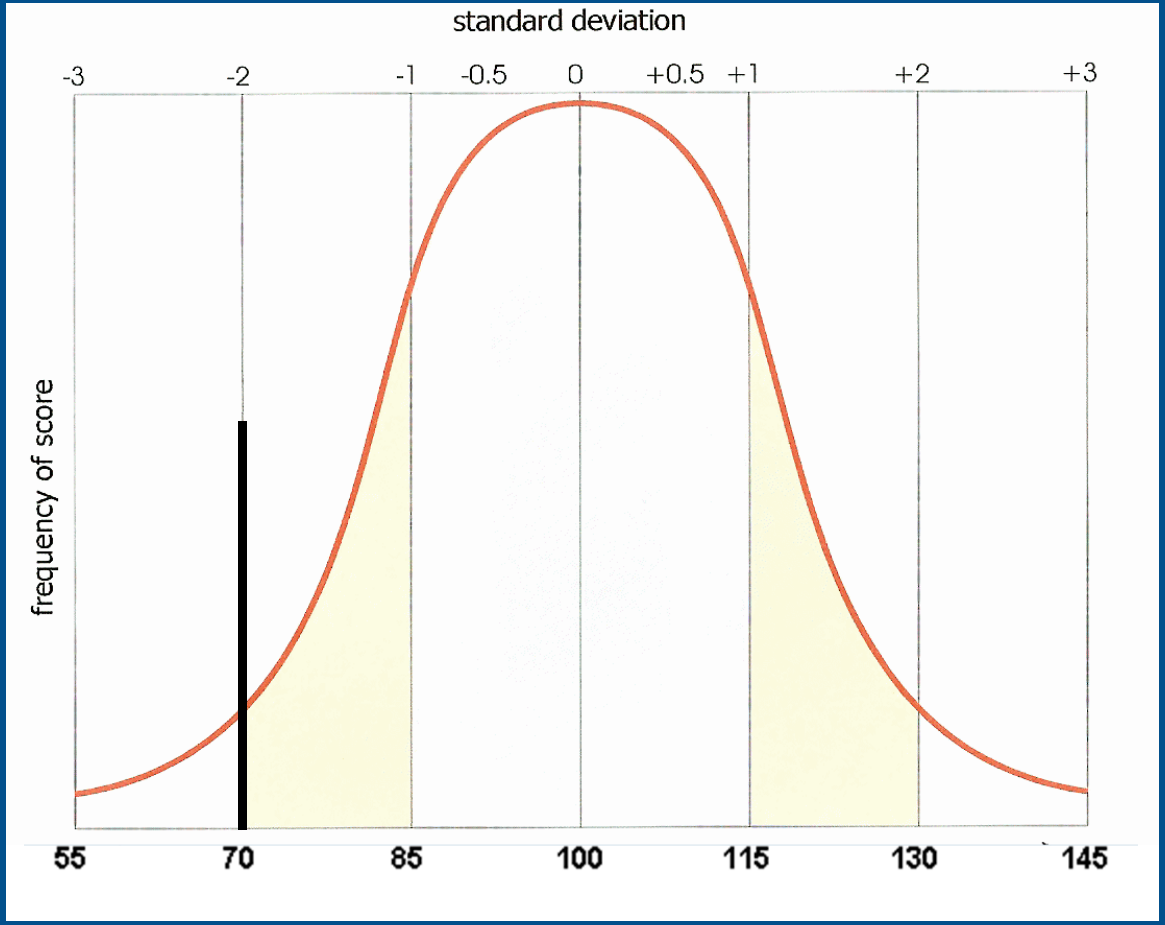
Intellectual Disability is “a condition of arrested or incomplete development of the mind … characterized by impairment of skills manifested during the developmental period which contribute to the overall level of intelligence, i.e cognitive, language, motor and social abilities”. [1]

Three elements must be present: [2]

- Intellectual impairment
- Associated social or adaptive dysfunction
- Early Onset

[1] World Health Organization. (1992). *ICD-10*.
[2] British Institute for Learning Disabilities (BILD). (2011). *Factsheet: Learning Disabilities*.

Impairment of IQ



Levels of ID

Mild = 50 - 69

Moderate = 35 - 49

Severe = 20 - 34

Profound = lower than 20

World Health Organization (WHO). (1992). *ICD-10*.

IQ & RFT

The behaviours measured by standard IQ tests can be understood as demonstrations of Derived Relational Responding.[1]

Studies on typically developing populations that have considered performance on RFT tasks and IQ measures have found that there is a correlation in performance.[2]

[1] Cassidy, Roche, & O'Hora. (2010). Relational Frame Theory and Human Intelligence. *European Journal of Behavior Analysis, 11*(1):37-51.

[2] Pelaez, O'Hora, Barnes-Holmes, Amesty, & Robinson. (n.d.). Performance on WAIS-III Relates to the Ability to Derive Relations.

IQ & RFT

IQ (WAIS-III) is correlated with (among others): Perspective taking abilities (deictic relational framing)[1], and temporal relational framing[2].

Programmes specifically targeting relational framing have raised IQ scores in typically developing children[3].

[1] Gore, Barnes-Holmes, & Murphy. (2010).
[2] O'Hora, Pelaez, Barnes-Holmes, Rae, Robinson, & Chaudhary. (2008).
[3] Cassidy, Roche, & Hayes. (2011).

Life Challenges

"People with intellectual disability … are at significantly increased risk of facing discrimination, social exclusion, and abuse. Children with intellectual disability are much more likely than their non-disabled peers to experience child poverty. As adults, people with intellectual disabilities are significantly less likely than their non-disabled peers to move out of their family home, have long-term intimate relationships, be employed, have friends and participate in the life of their communities. They are also more likely to live in poor health, have poorer mental health and to die young. These inequalities transcend national boundaries."

Eric Emerson

Carr et al. (Eds). (2014). *The Handbook of Intellectual Disability and Clinical Psychology Practice*. Routledge.

Psychological Distress

People with ID experience mental ill-health and psychological distress at least as much as the typically-developing population does.[1]

Within the ACT model, verbal processes contribute to psychological distress through psychological inflexibility.

Although people with ID have impairments in the verbal language skills, there is no reason to suspect that verbal processes and psychological inflexibility are not implicated.

The broad challenge is to intervene at the level of these processes in an effective way.

[1] Carr et al. (Eds). (2014). *The Handbook of Intellectual Disability and Clinical Psychology Practice*. Routledge.

ID & ACT - challenges

Attention span likely to be limited

Verbal ability likely to be reduced

Ability to use metaphor likely to be reduced

Ability to use Deictic framing likely to be underdeveloped

Impulse control and emotional regulation may be impaired

Ability to engage with meta-cognitions may be limited

Influence over what they do with their lives will frequently be compromised through the presence of paid and unpaid carers

Lesson learned #1

We don’t have much evidence

ID & ACT: Evidence

The evidence base for ACT within ID is limited.

Jackson Brown and Hooper (2009) successfully applied the ACT model in the treatment of a young woman with ID who was experiencing anxious and obsessive thoughts.

Sarah was assessed as having a full-scale IQ of 44 (moderate ID).

The therapy process required adaptation but Sarah was able to work with language and metaphor. She experienced a reduction in her distress at her thoughts.

Jackson Brown & Hooper (2009). Acceptance and Commitment Therapy (ACT) with a learning disabled young person experiencing anxious and obsessive thoughts. *Journal of Intellectual Disabilities, 13*(2): 195-201.

ID & ACT: Evidence

Pankey & Hayes (2003) described a four-session ACT intervention for a young woman with psychosis and ID.

She was assessed as having a full-scale IQ of 58 (mild ID).

Although not specifically targeted, there were improvements in overeating, dismantling appliances, and sleeping.

Medication compliance was specifically targeted and it too showed improvement.

Pankey, J., & Hayes S.C. (2003). Acceptance and Commitment Therapy for Psychosis. *International Journal of Psychology and Psychological Therapy, 3*(2):311-328.

ID & ACT: Evidence

… and that's it.

ARTICLE

Acceptance and Commitment Therapy (ACT) with a learning disabled young person experiencing anxious and obsessive thoughts

FREDDY JACKSON BROWN North Bristol NHS Trust, UK

SIAN HOOPER North Bristol NHS Trust, UK

Journal of Intellectual Disabilities

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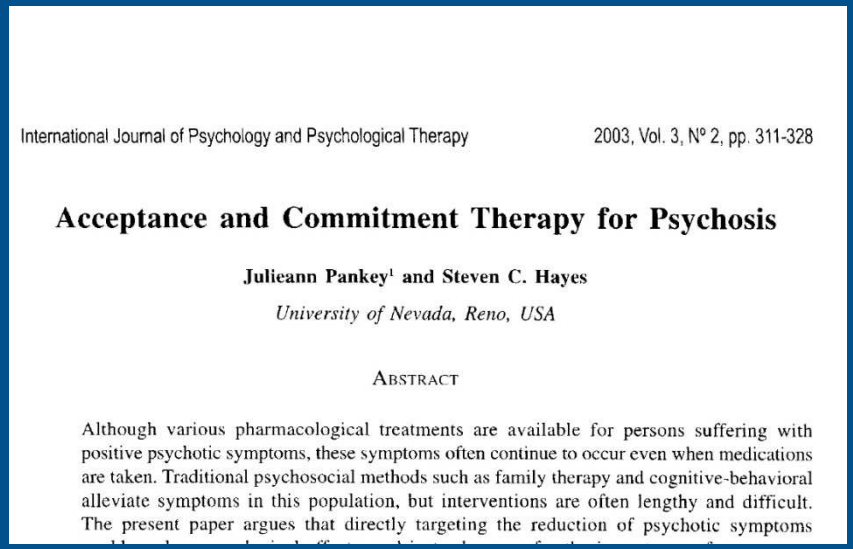
DOI: 10.1177/1744629509346173



International Journal of Psychology and Psychological Therapy 2003, Vol. 3, Nº 2, pp. 311-328

Acceptance and Commitment Therapy for Psychosis

Julieann Pankey[1] and Steven C. Hayes

University of Nevada, Reno, USA

ABSTRACT

Although various pharmacological treatments are available for persons suffering with positive psychotic symptoms, these symptoms often continue to occur even when medications are taken. Traditional psychosocial methods such as family therapy and cognitive-behavioral alleviate symptoms in this population, but interventions are often lengthy and difficult. The present paper argues that directly targeting the reduction of psychotic symptoms

Lesson learned #1

We need more evidence.

Hoffman et al. (2016) have made precisely this point. They suggest that ACT would be a useful addition to standard ABA and put out a call for research.

Our team is preparing a review paper in which we intend to summarise what little is out there in the academic and grey literatures.

We plan to cover direct work, ACT with carers and parents, and also clarify which papers we can exclude due to confusions around terminology.

Hoffmann, Contreras, Clay, & Twohig. (2016). Acceptance and Commitment Therapy for Individuals with Disabilities: A Behavior Analytic Strategy for Addressing Private Events in Challenging Behavior. *Behavior Analysis in Practice*.

Lesson learned #2

Challenges in accruing evidence:
We don’t have an adapted / accessible measure of psychological flexibility

Challenges in accruing evidence

If there is to be more evidence published, the field needs to be able to demonstrate that ACT interventions are targeting the desired processes.

We need measures of psychological flexibility that are accessible to clients with more significant levels of intellectual disability.

Case Example

Andy.

19 years old.

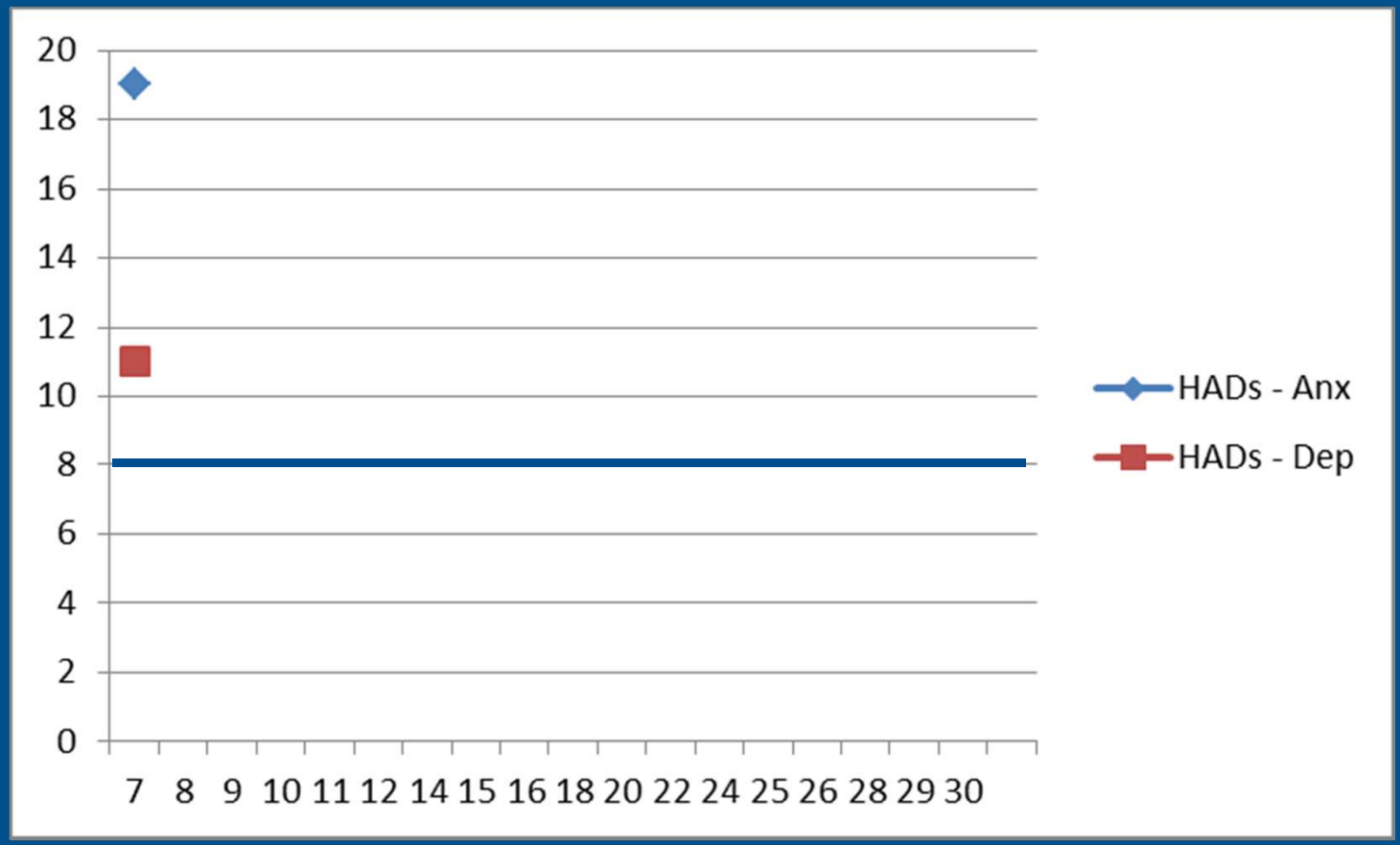
Mild ID and autism.

Living at home with his parents and younger brother.

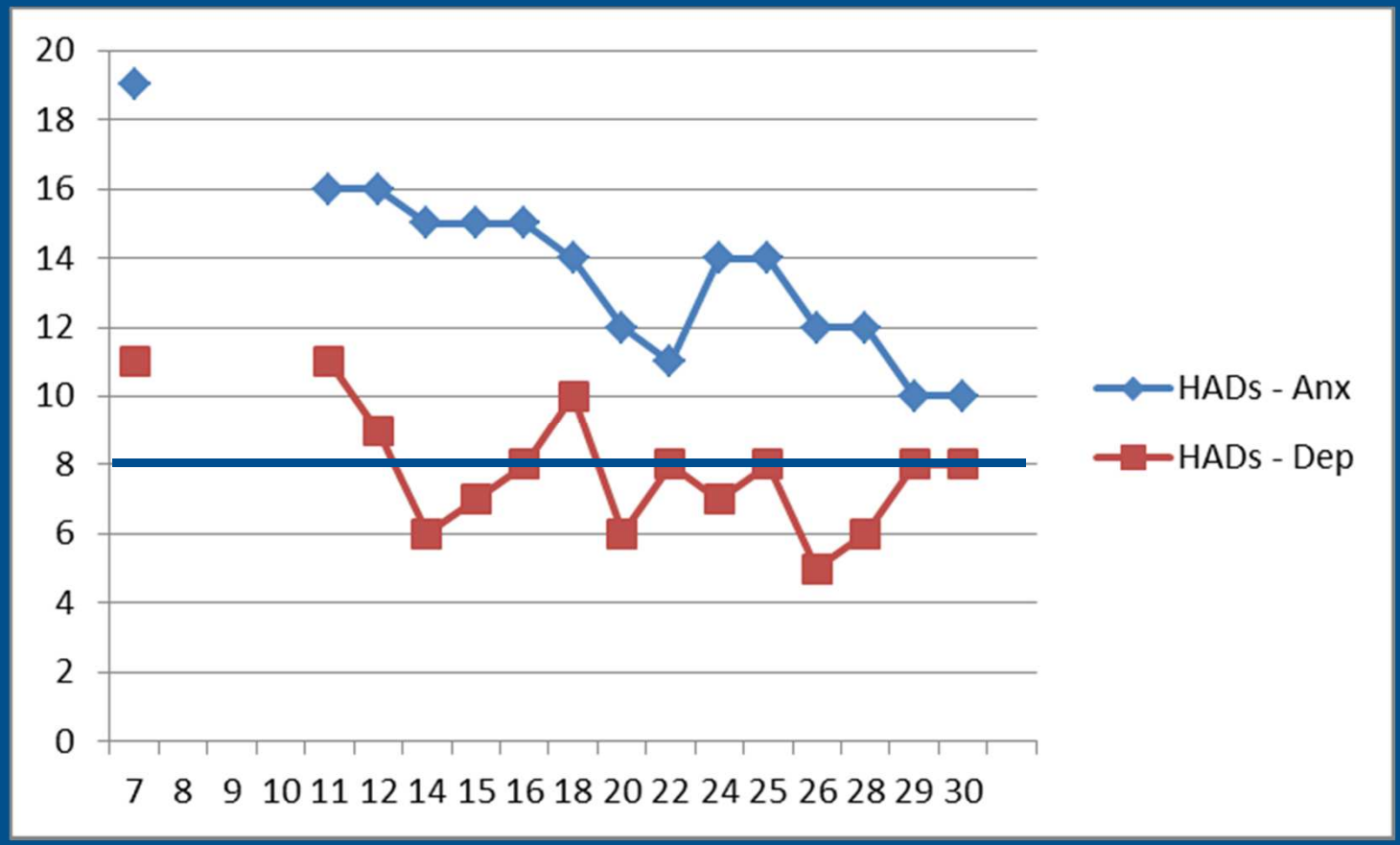
Referred for obsessive thoughts about his family coming to harm. He is restricting their activities to a point where it is causing problems within the relationships.

Had been in Children's and Young People's Services for this since the age of five.

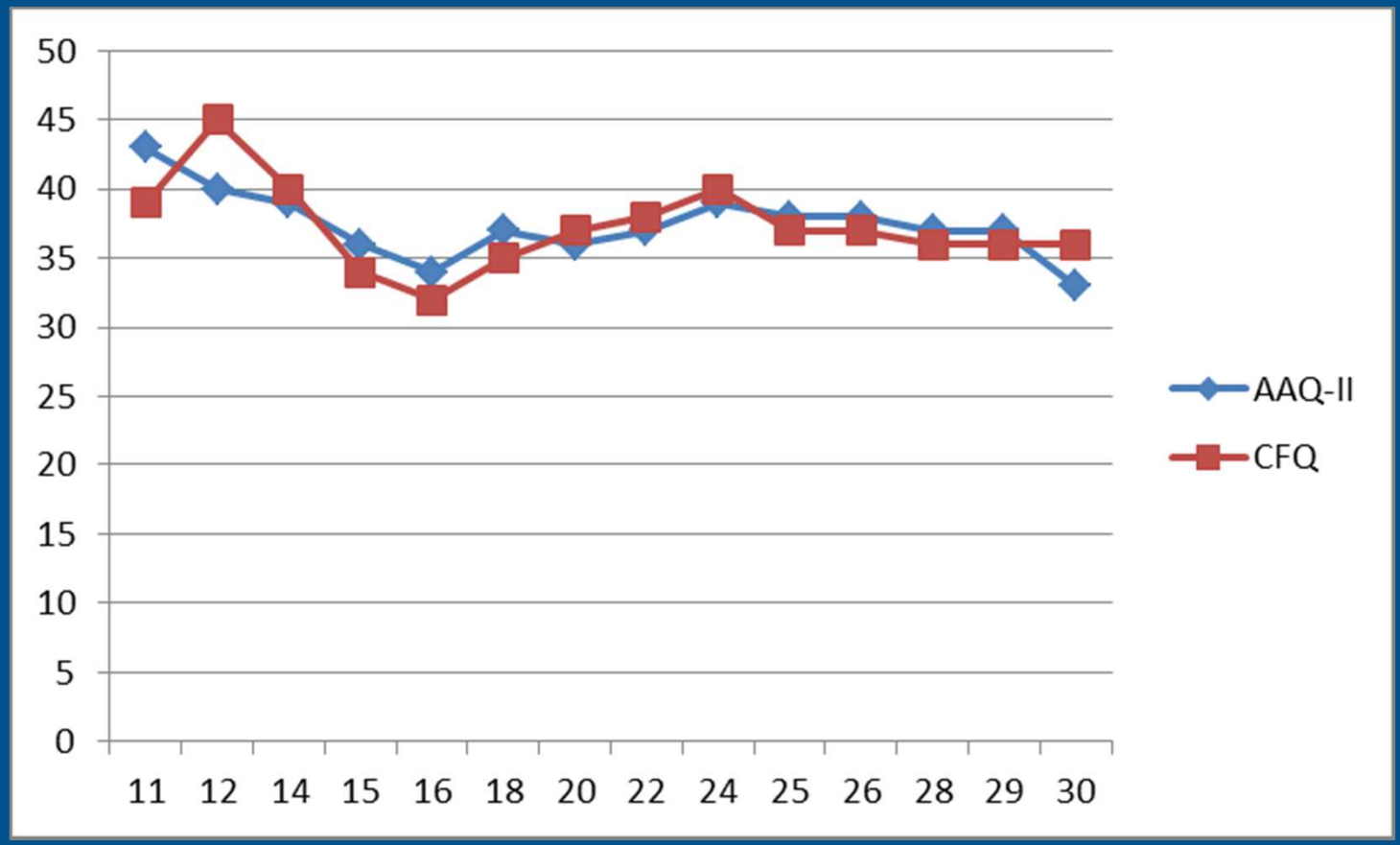
Anxiety and Depression Scores



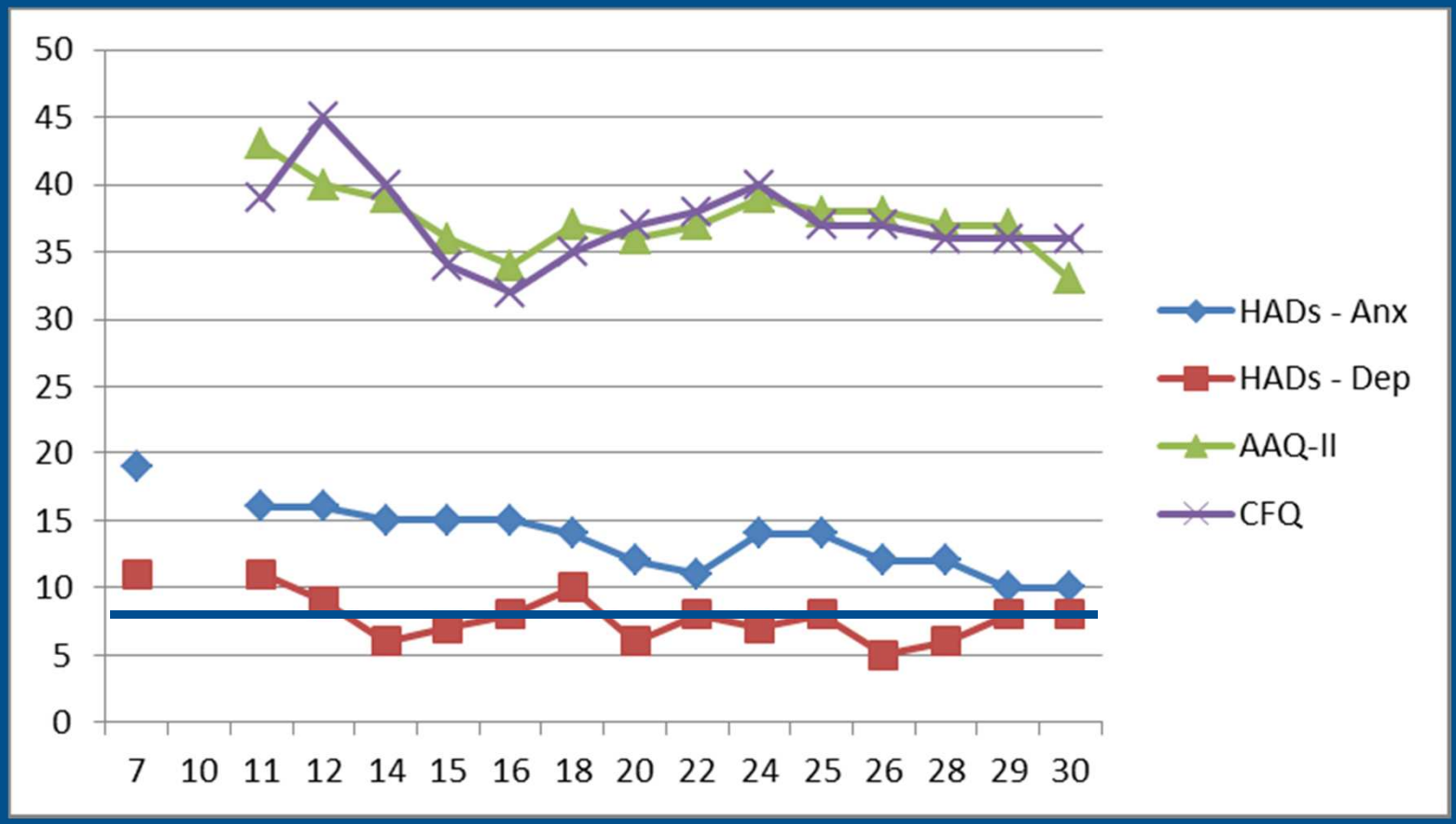
Anxiety and Depression Scores



Psychological Flexibility Scores



Psychological Flexibility Scores



Lesson learned #2

Being able to measure and track Andy's psychological flexibility allowed us not to read too much into symptom improvement.

We could do this because Andy had good verbal language skills, but he is at the upper end of ability for our client group.

We need measures of psychological flexibility that are accessible to clients with more significant levels of intellectual disability.

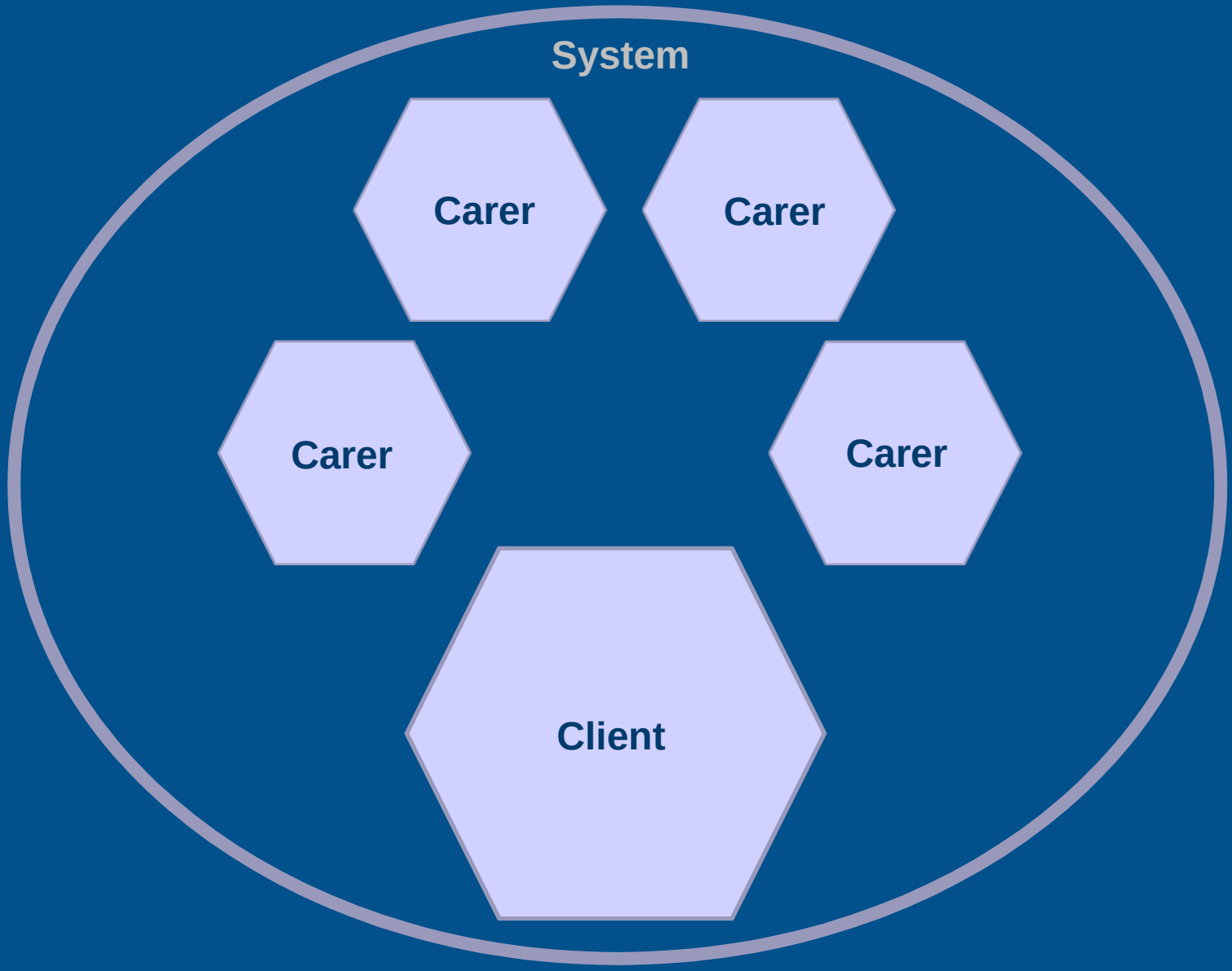
Lesson learned #3

Our clients live within systems of influence that reduces their ability to change their behaviours

ID and Carers

Because people with ID have deficits in adaptive functioning, they will frequently have paid and unpaid carers in their lives.

The input and influence of these carers is likely to have an impact on the success of therapy.


System
Carer
Carer
Carer
Carer
Client

Case Example

Amanda was in her 50s and was no longer able to care for herself due to morbid obesity that meant she could not move unaided.

Mild ID.

Went to live in a nursing home, where she was the youngest by many years.

Presented as anxious and depressed.

Engaged well with mindfulness, we began work on values. She loved gardening. We agreed that in moving towards this she would commit to planting one seed in one pot.

The staff found this unacceptable and prevented it from happening.

Case Example

Deborah was in her 30s and had for two years had intrusive thoughts of stabbing people with a knife. She had kept these thoughts to herself, but when she finally disclosed them she lost her voluntary job (preparing sandwiches) and was no longer allowed to do cooking and vegetable peeling in the home. She became bored, depressed and anxious. With nothing to fill her time she spent her time worrying about stabbing people.

Mild – moderate ID.

She responded quickly to defusion work and stopped being troubled by her thoughts; their intensity and frequency dropped accordingly.

Staff continued to refuse to allow her access to knives because she had experienced thoughts, even though the risk (as informed by past behaviours and by her horror at the thought of hurting anyone) was objectively low.

Case Example

Cassie was a 38 year old woman with mild intellectual disabilities and a diagnosis of emotionally unstable personality disorder.

Her support staff misunderstood the Passengers on the Bus metaphor and at times of distress were telling her to throw her unwanted passengers off her bus and to think positively instead.

Lesson learned #3

People with Intellectual Disabilities frequently experience barriers to acting in accordance with their values.

They may also have to contend with ACT–inconsistent messages being conveyed to the client (distraction, PRN medication etc) that could be reinforcing experiential avoidance and working against the grain of therapy.

Clinicians working directly with this client group would be advised to take into account the broader systems that and incorporate some carer-level work.

Lesson learned #4

Deficits in verbal behaviour / relational framing may hamper therapeutic efforts

ID & RFT Deficits

In Mastering The Clinical Conversation, Villatte, Villatte & Hayes outline the kinds of interventions that could be expected to facilitate increased psychological flexibility, eg:

- "Use **perspective taking** to gain insight: **Interpersonal deictic framing**, […] **Spacial deictic framing**, […] **Temporal deictic framing**".
- "Use **hierarchical framing** to connect responses to a higher purpose."
- "Use **opposition framing** to create a lighter context."
- "Use **coordination framing** to make psychological consequences compatible with meaningful actions".

Villatte, Villatte, & Hayes. (2016). *Mastering the Clinical Conversation*.

ID & RFT Deficits

Unfortunately…
People with Intellectual Disabilities are much less able to demonstrate relational framing behaviours than the typically developing population.

The specific verbal skills we might attempt to utilise for therapeutic gain may be misguided – if our client with ID has temporal framing deficits, targeting temporal framing is unlikely to lead to increased wellbeing.

This goes for any of the relational framing interventions (derived relational responding skills) we might try.

Lesson learned #4

When working with an ID population, your client may not be able to demonstrate the relational framing skills you are attempting to use therapeutically, or may only be able to use very simple versions of them, or may not be able to use them consistently, or may use them in an idiosyncratic way.

Greater therapeutic gain may follow targeting of those relational framing skills they can use.

If DRR skills are notably absent, an educational skill-building programme bolstering deficient relational framing skills may be required before these skills can be applied for therapeutic gain.

Summary & Conclusion

People with Intellectual Disabilities struggle with mental ill health in numbers at least as great as those found in the typically developing population.

Mental ill health / psychological distress is considered within the ACT model to be as a result of normal verbal processes that become overly dominant, and the subsequent efforts to remove or diminish their impact.

There is no reason to think that this process does not apply to people with intellectual disabilities, and therefore ACT should be an appropriate therapy.

In our work with adults with Intellectual Disabilities we have learned a number of lessons.

Summary & Conclusion

Lesson 1 – There is very little evidence to guide us; as a community of clinicians working with ID we need to publish more.

Lesson 2 – Publishing requires data, and we therefore need to adapt measures of psychological flexibility to meet the needs of this population.

Lesson 3 - We need to take into account the influence of paid and unpaid carers.

Lesson 4 – People with ID are likely to have deficits in particular areas of relational framing. Intervention strategies based on these might not be as effective as in a typically developing population.

Thanks to all of the clients discussed for allowing me to present aspects of their cases.

Join us!
We have a Google Group **CBS4ID**
To join, send an email to cbs4id@googlegroups.com

Contact:
Mark.Oliver@NTW.NHS.UK

Shining a light on the future

Northumberland, Tyne and Wear NHS
NHS Foundation Trust

Group Based Mindfulness Intervention built on ACT principles for Adults with Intellectual Disabilities

Steve Noone PhD BCBA-D

ACBS World Conference, Seville

24th June 2017

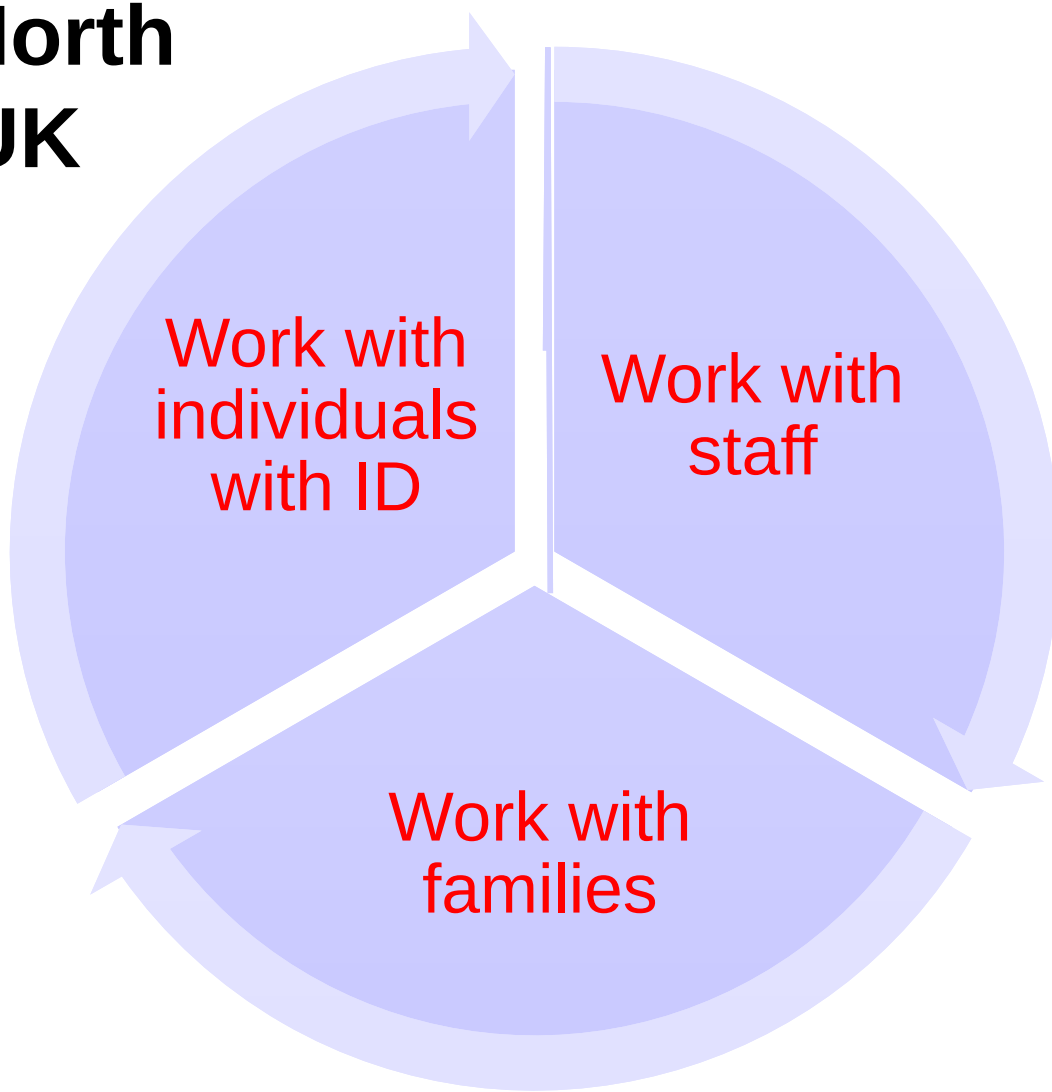
Disclosures (support):

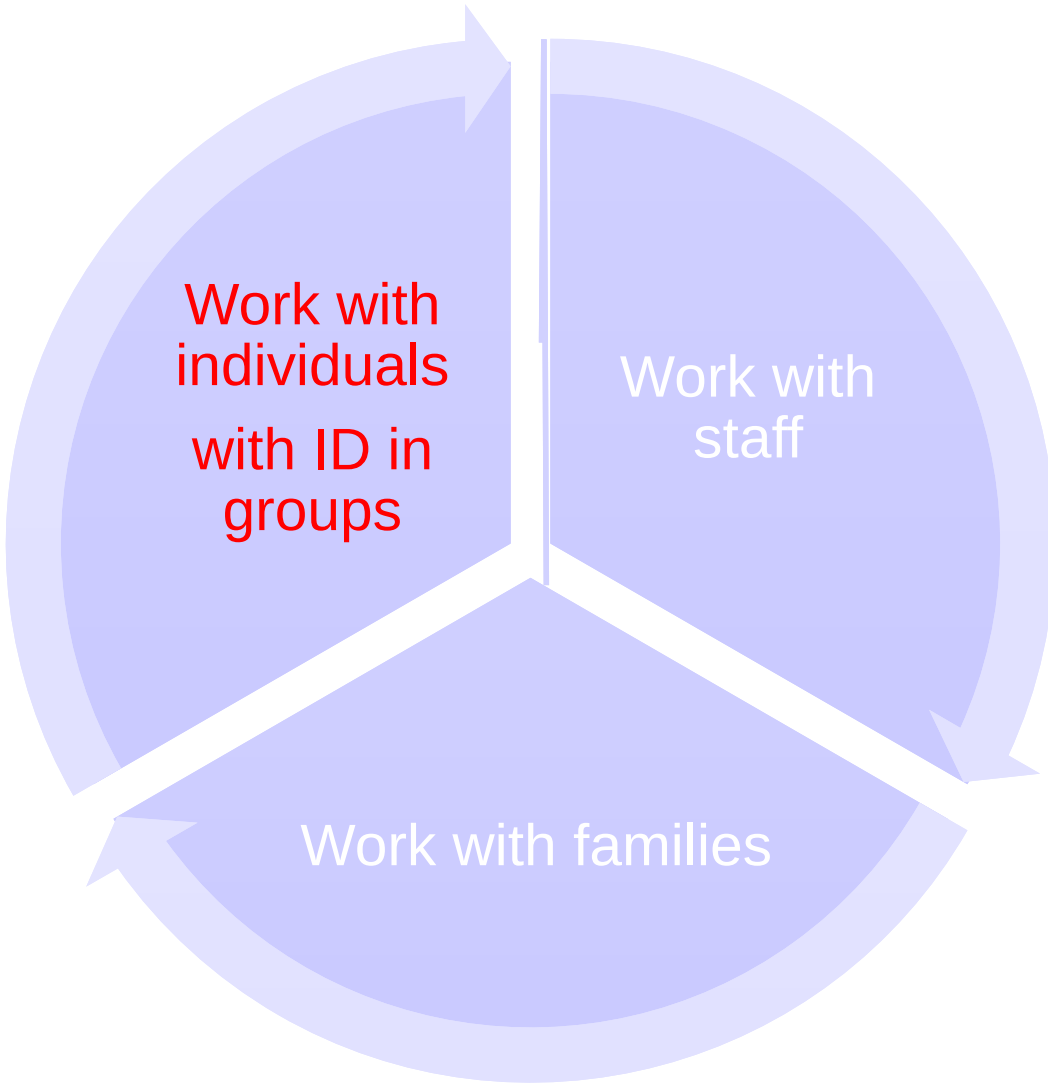
Steve Noone

Relevant Financial Relationships:

- employed in **NHS**
- adjunct faculty **Bangor University**
- research partially funded by grant from the **Health Education North East**

ACT in North East of UK with People with ID




Work with individuals with ID in groups
Work with staff
Work with families

Mindfulness for Life

Skills for people
changing lives

Northumberland, Tyne and Wear NHS
NHS Foundation Trust

Relevant research

- The use of mindfulness with people with ID and carers: systematic reviews

  (Chapman, et al; 2013, Hwang et al 2013a 2013b)

Mindfulness interventions for people with ID

- ***Soles of the Feet*** - (Singh et al 2003 - 2013; Idusohan-Moizer et al, 2013)

- ***Mindful Observation of Thoughts*** – visualising and observing thoughts as clouds passing through awareness (Singh et al 2011b)

- ***Mindfulness programmes*** –to promote non-judgemental attitudes and acceptance, awareness of surroundings and thoughts and breathing (Chilvers et al 2011);

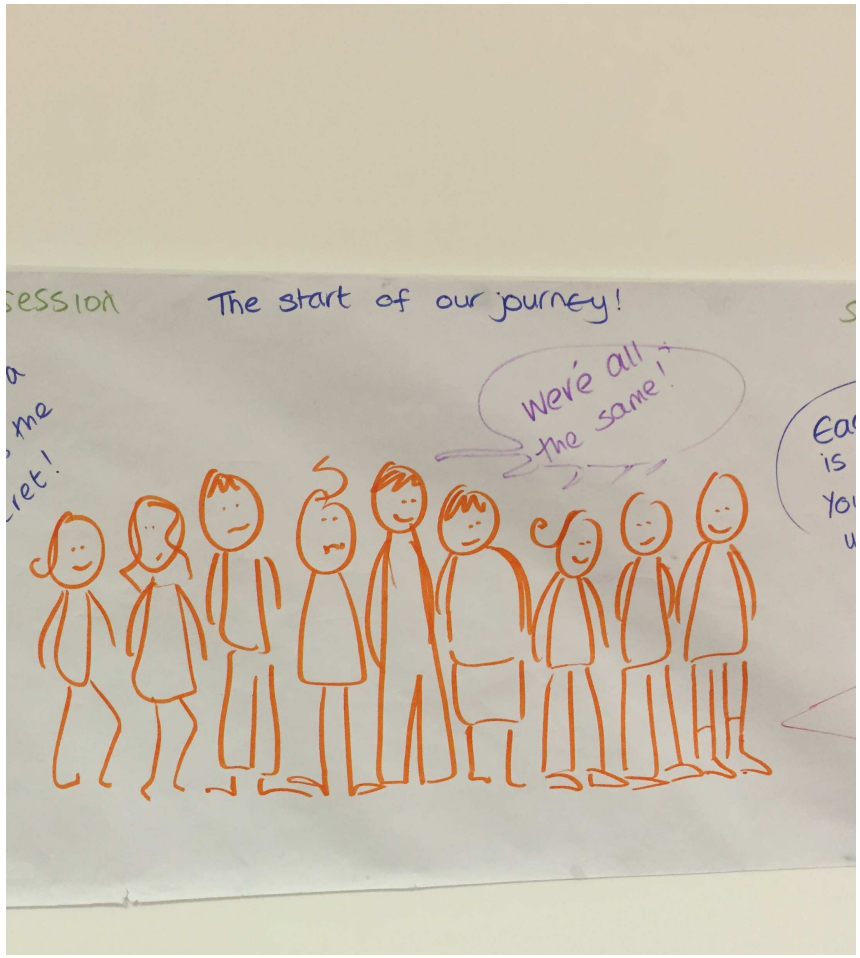
  MBCT programme (Idusohan-Moizer et al, 2013)

Key findings

All studies found improvements over medium-long term:

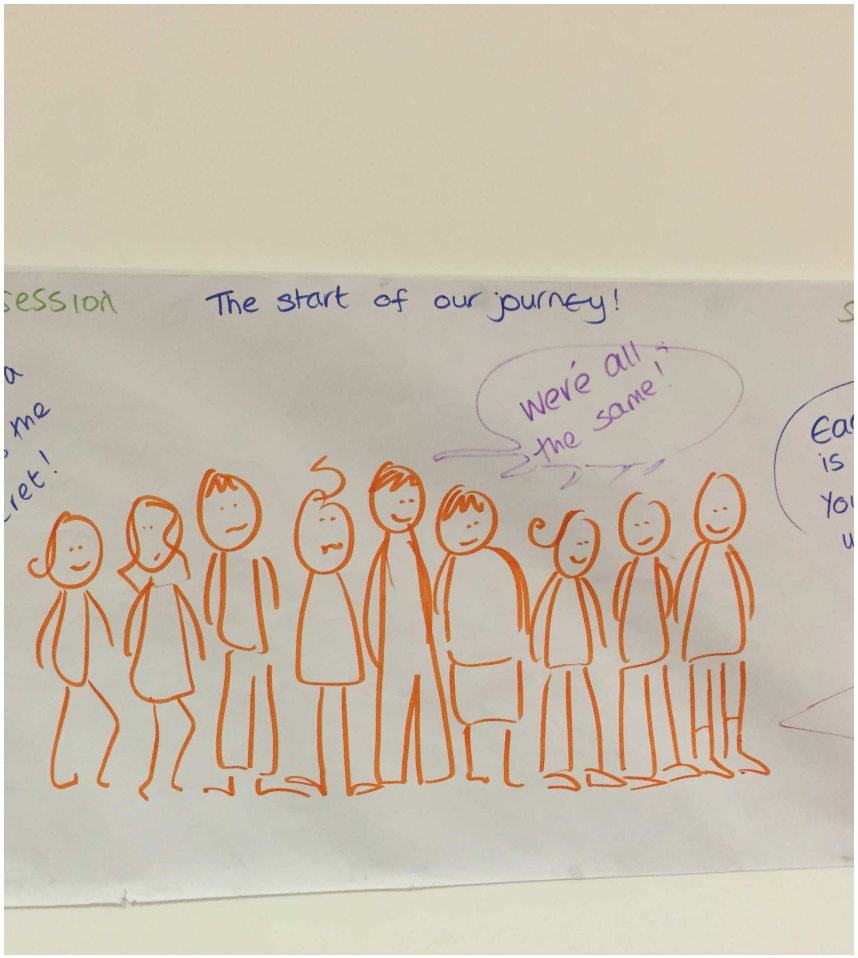
- **Physical and verbal aggression** (Singh et al 2003, 2007a, 2008b, 2013, Adkins et al 2010, Chilvers et al 2011, Singh et al 2011c)
- **Increases in self control** (Singh et al 2003, 2008b), compassion towards self and others (Idusohan-Mozer et al 2013)
- **Improvements in psychological wellbeing, anxiety and depression** (Adkins et al 2010; Idusohan-Mozer et al 2013; Miodrag et al 2013)
- **Reductions in inappropriate sexual arousal** (Singh et al 2011b)
- **Physiological changes** – declines in cortisol and sAA levels (Miodrag et al 2013)

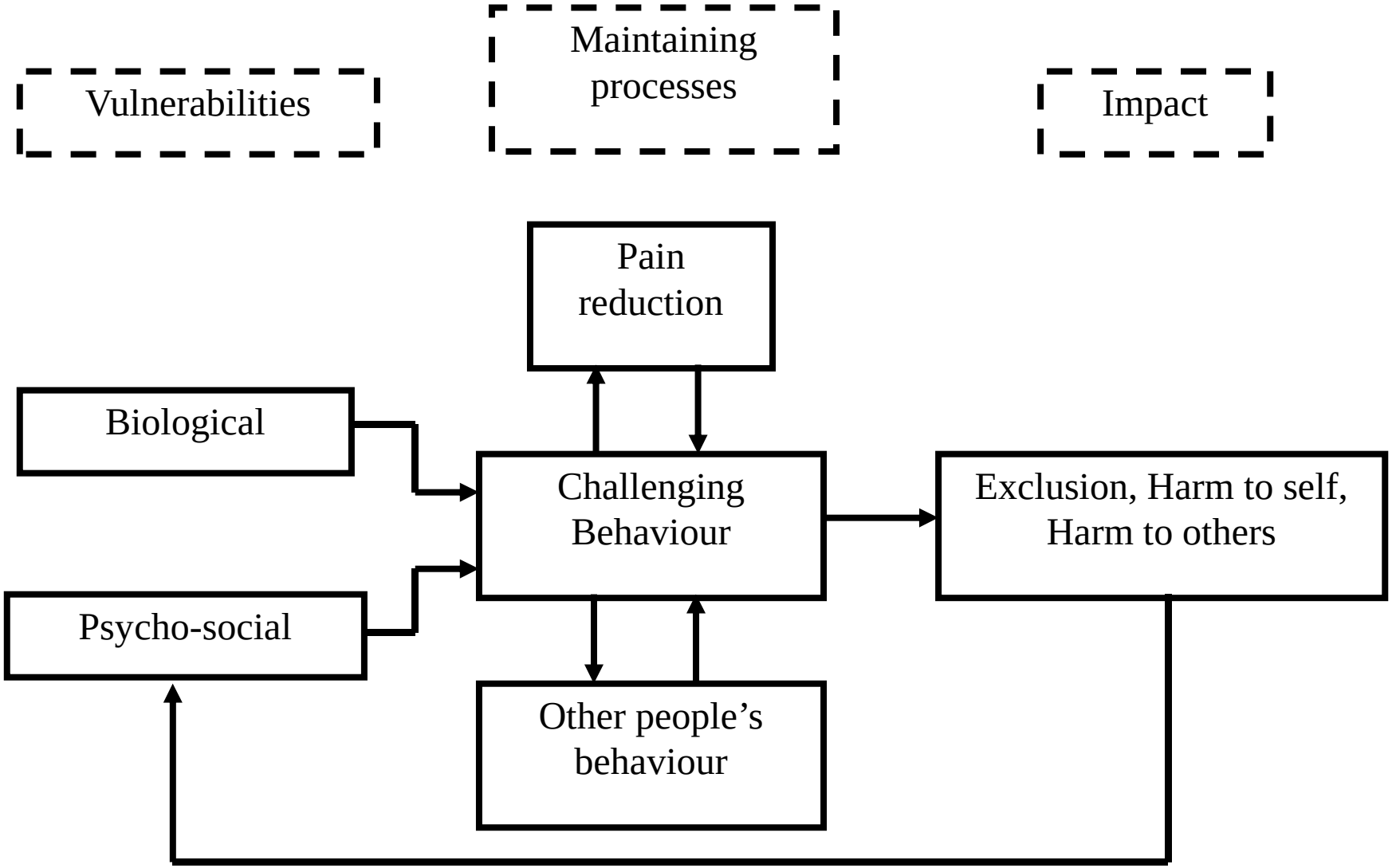
Why develop a group?



Why develop a group?

- Increased vulnerability



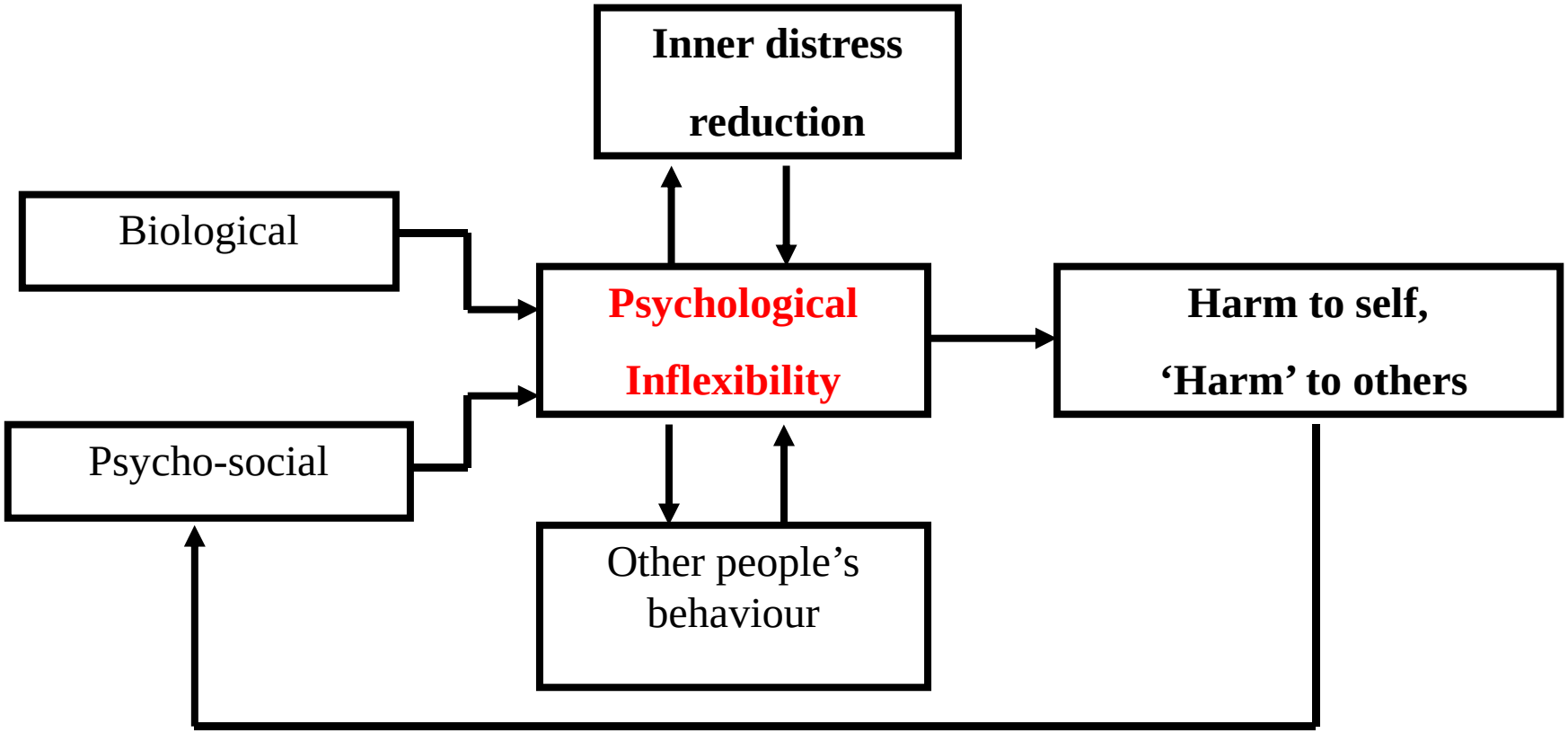


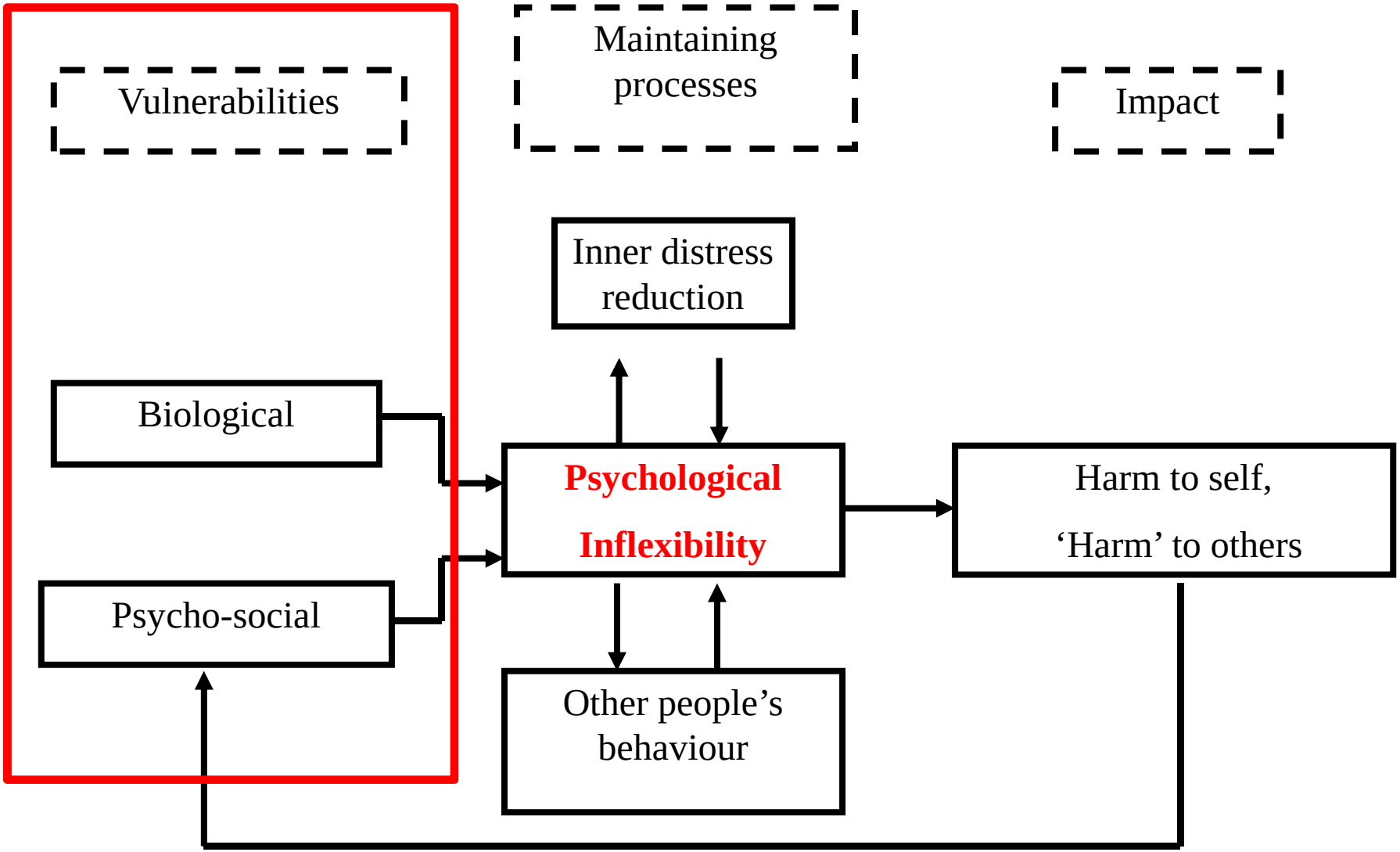
From Hastings et al. *International Journal of PBS*, December 2013

Vulnerabilities

Maintaining processes

Impact



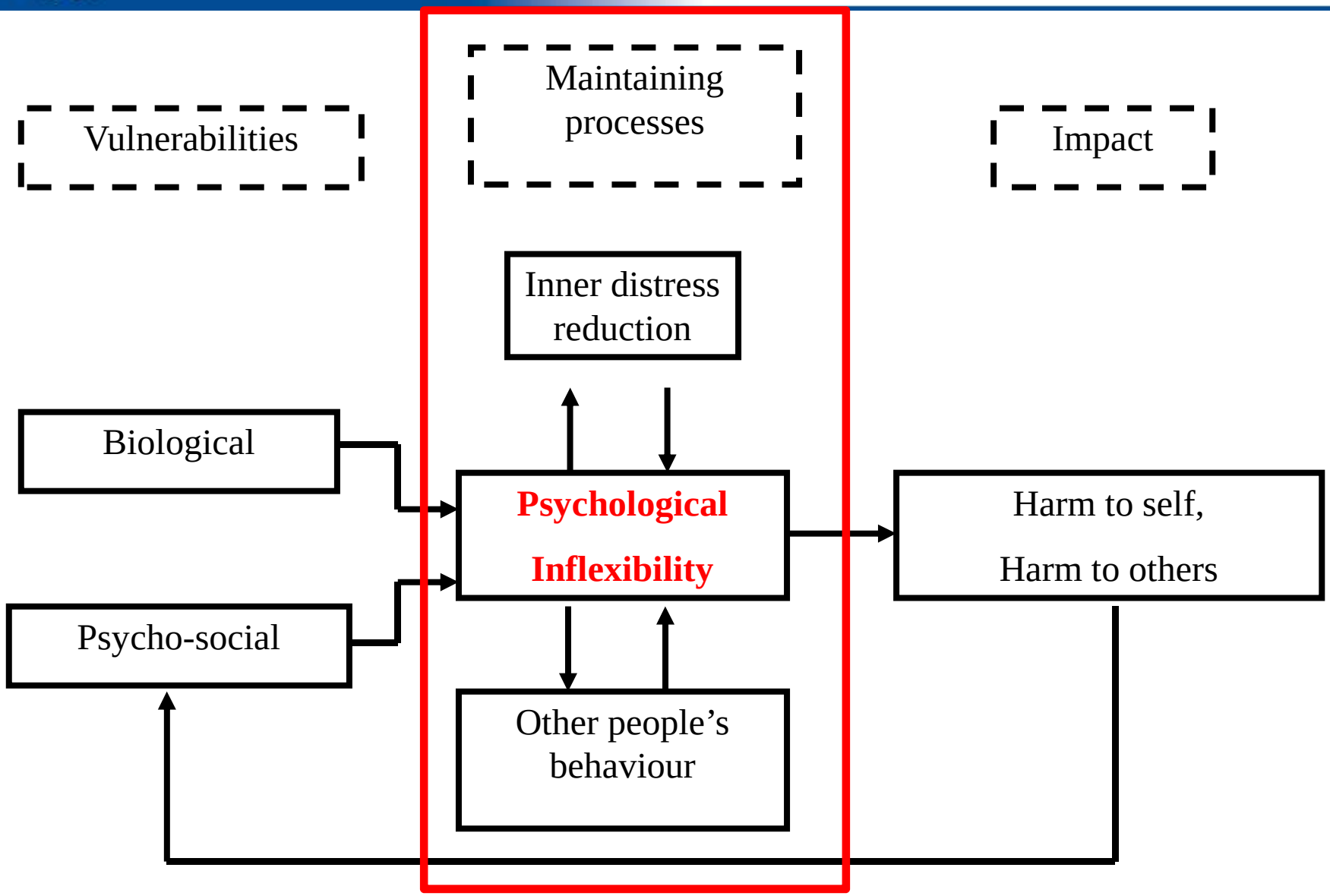

Vulnerabilities
Maintaining processes
Impact
Inner distress reduction
Biological
Psycho-social
Psychological Inflexibility
Harm to self,
'Harm' to others
Other people's behaviour

Why develop a group?

- Increased vulnerability
- Reduced personal resources
- Socially isolated

Why develop a group?

- Increased vulnerability
- Reduced resources
- Socially isolated
- Require a ‘system’ of support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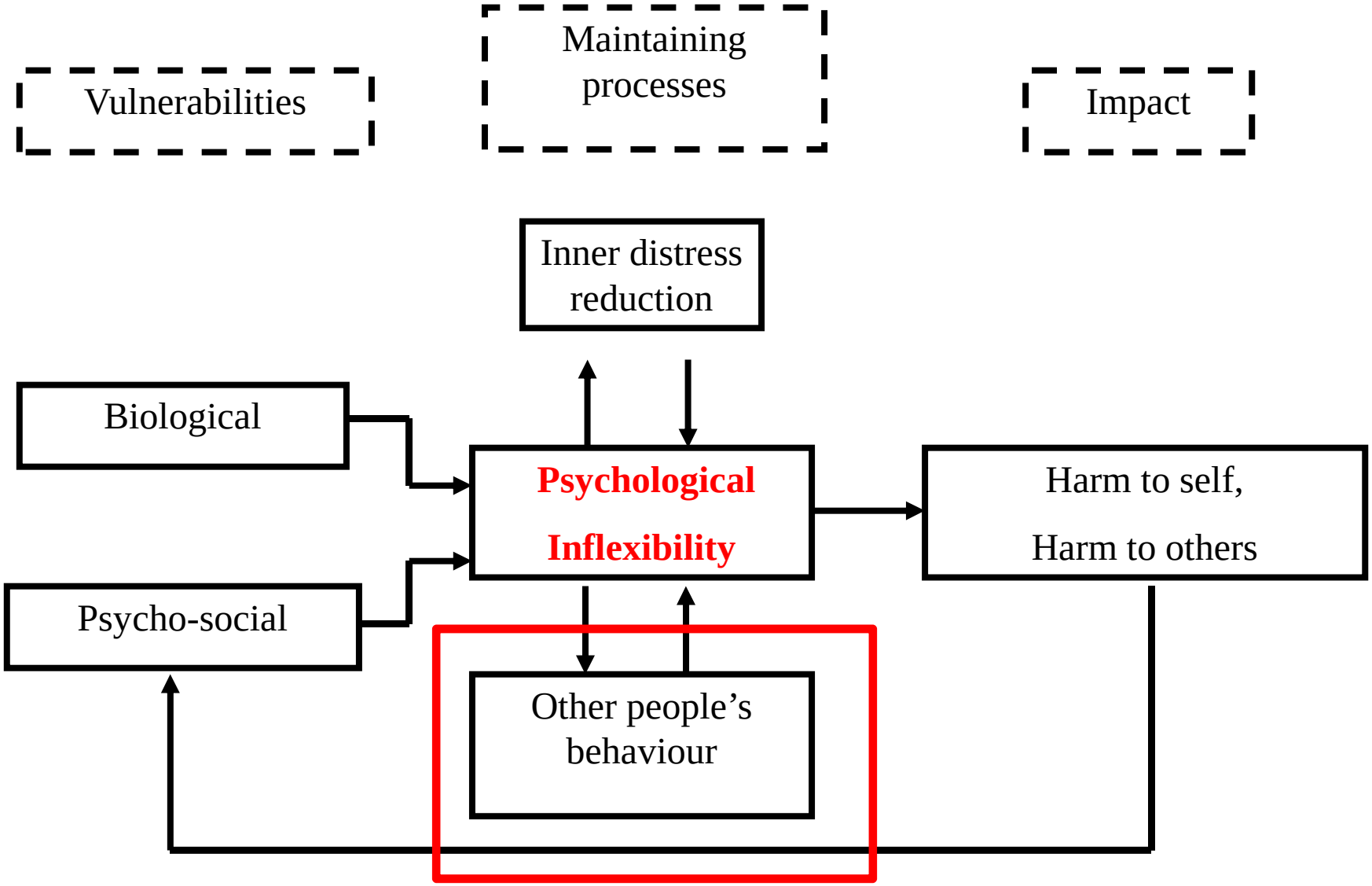
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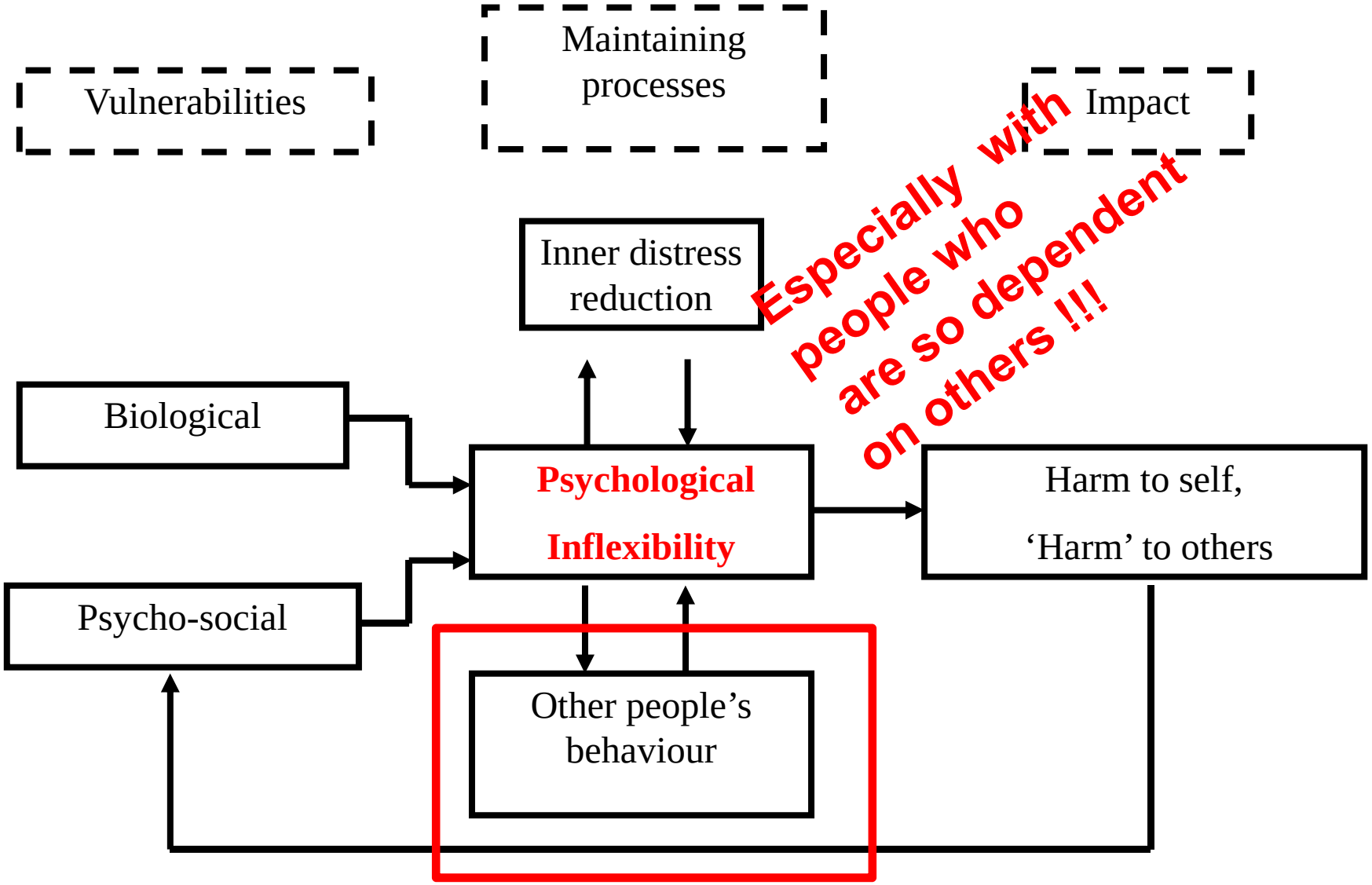
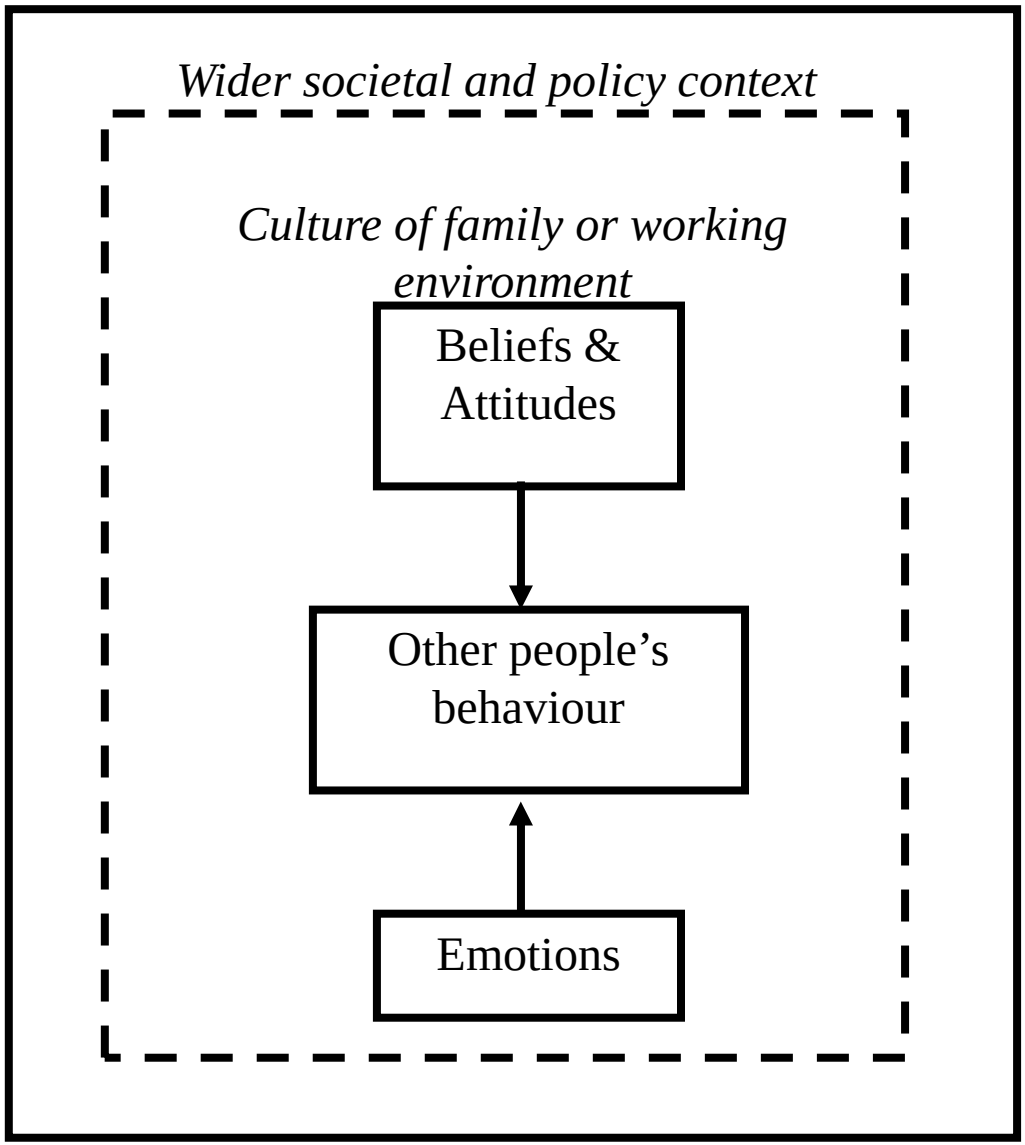

Vulnerabilities
Maintaining processes
Impact
Inner distress reduction
Especially with people who are so dependent on others !!!
Biological
Psychological Inflexibility
Harm to self,
'Harm' to others
Psycho-social
Other people's behaviour



From Hastings et al., 2013

Adapted from Hutchinson, Hastings et al., 2014 *Journal of Intellectual Disability Research*

Why develop a group?

- Increased vulnerability
- Reduced resources
- Socially isolated
- Require a ‘system’ of support
- Work with support workers
- Shape services

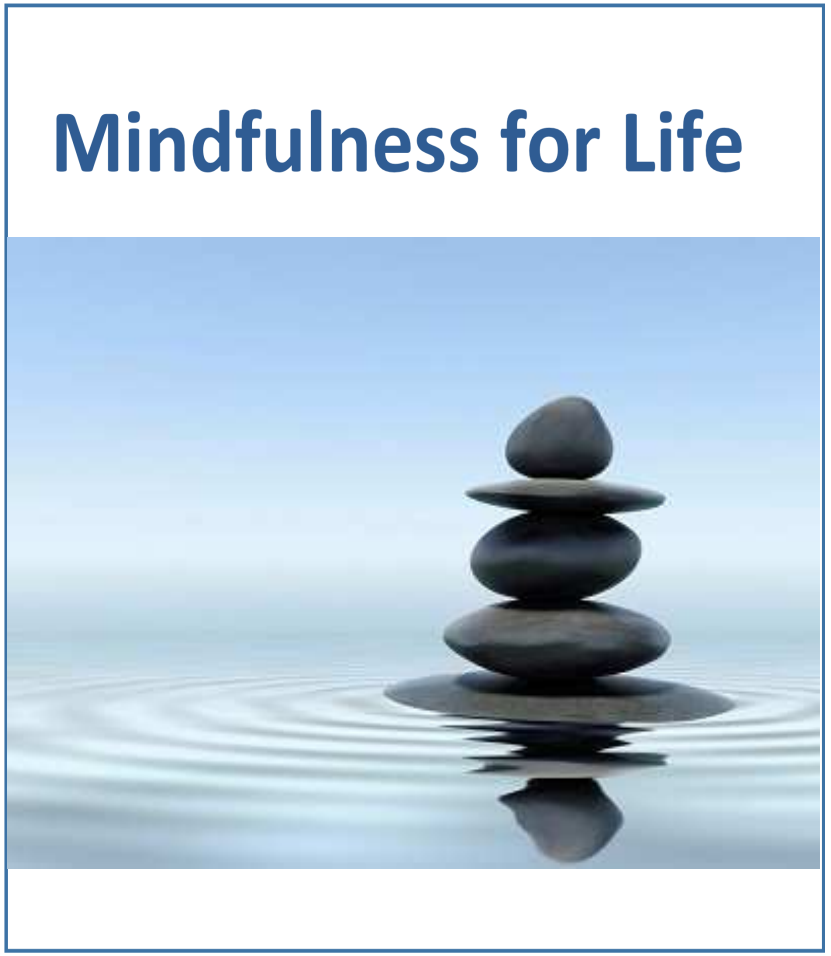
Why mindfulness?

- Low concept content
- Mindfulness equals ‘Heartfulness’

  (Kabat-Zinn)
- When we all close our eyes and just breath.. who has a disability?

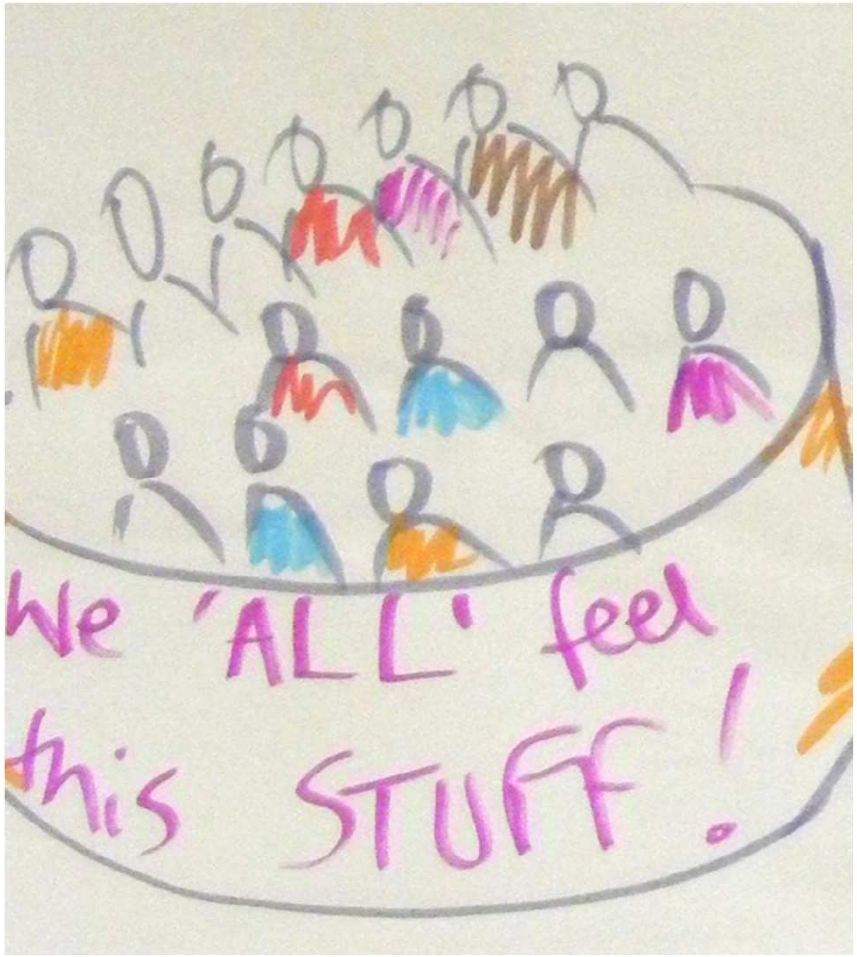
What sort of group ?

1. Collaboration with self advocacy groups
2. Invite support workers to take part
3. MBSR spine
4. ACT makes more it accessible
5. Delivered with person with ID



What can ACT offer ?

- Values focus
- Normalising suffering
- Central mantra about new relationship with thoughts
- Metaphor of monster mind



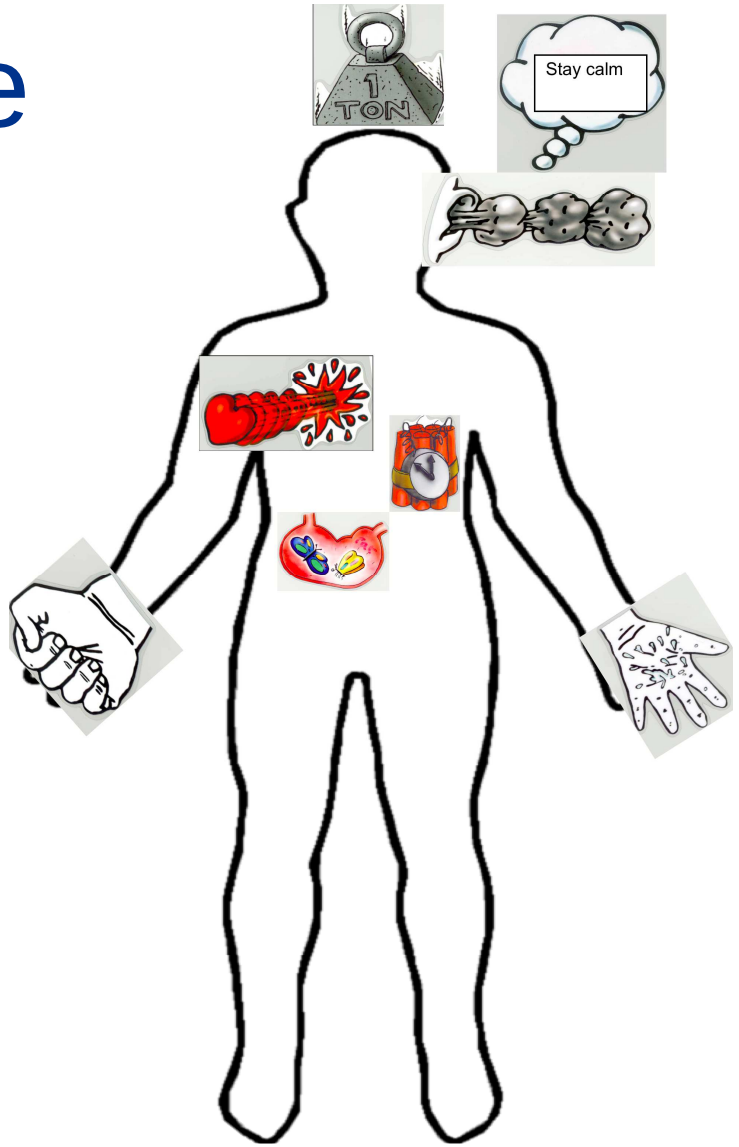
Over view

1. **Structure**
- Four cohorts 9 – 11 weeks
- Workshop + practice session
2. **Numbers of people**
- Over 100 attend taster session
- 6 – 27 regularly attend
3. **Outcome**
- Evolution from group to community

1. Central narrative This being human can be tough:

We all have a secret ……

And it's the same secret

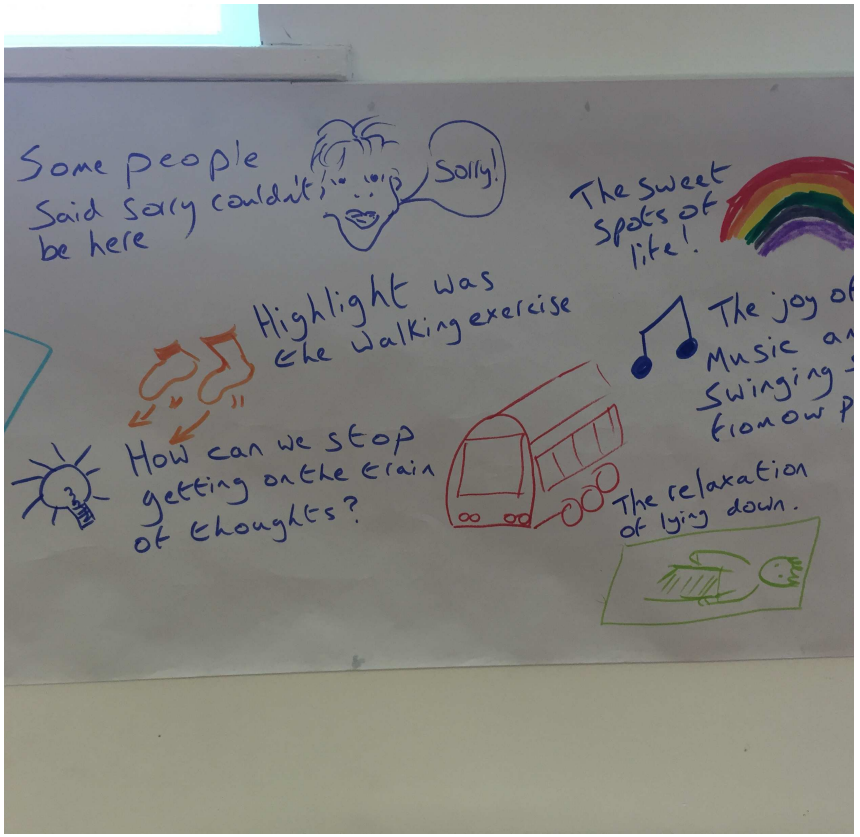


2. Central narrative:

- What do we do when sadness, anger and fear turn up?
- The guest house: We all need to find a way of living with unwanted visitors!

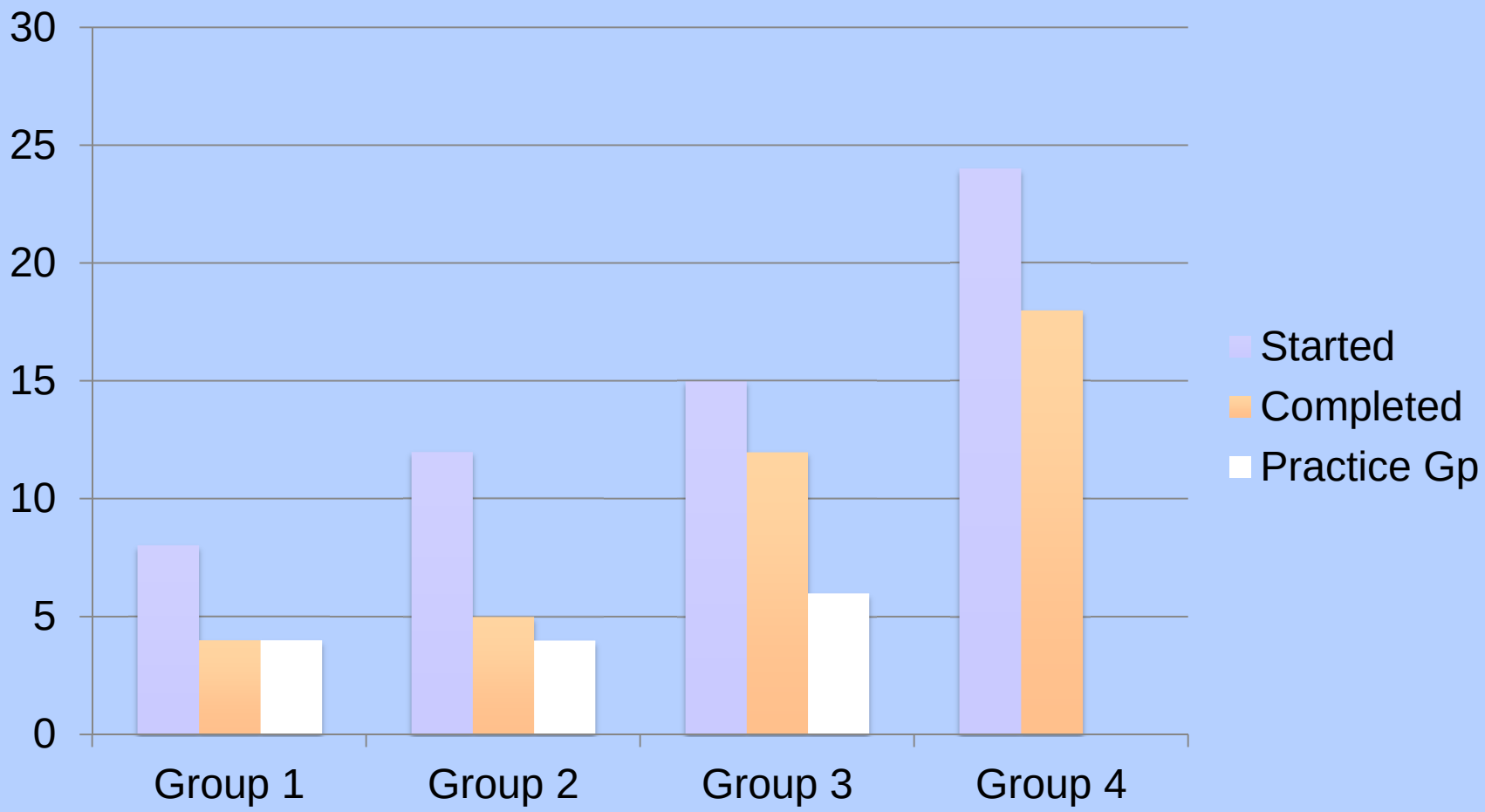
Central narrative

- Re-body
- Get off the thought train
- Noticing auto-pilot
- Be available for the sweet spots
- Practice and share together



Make up of the course

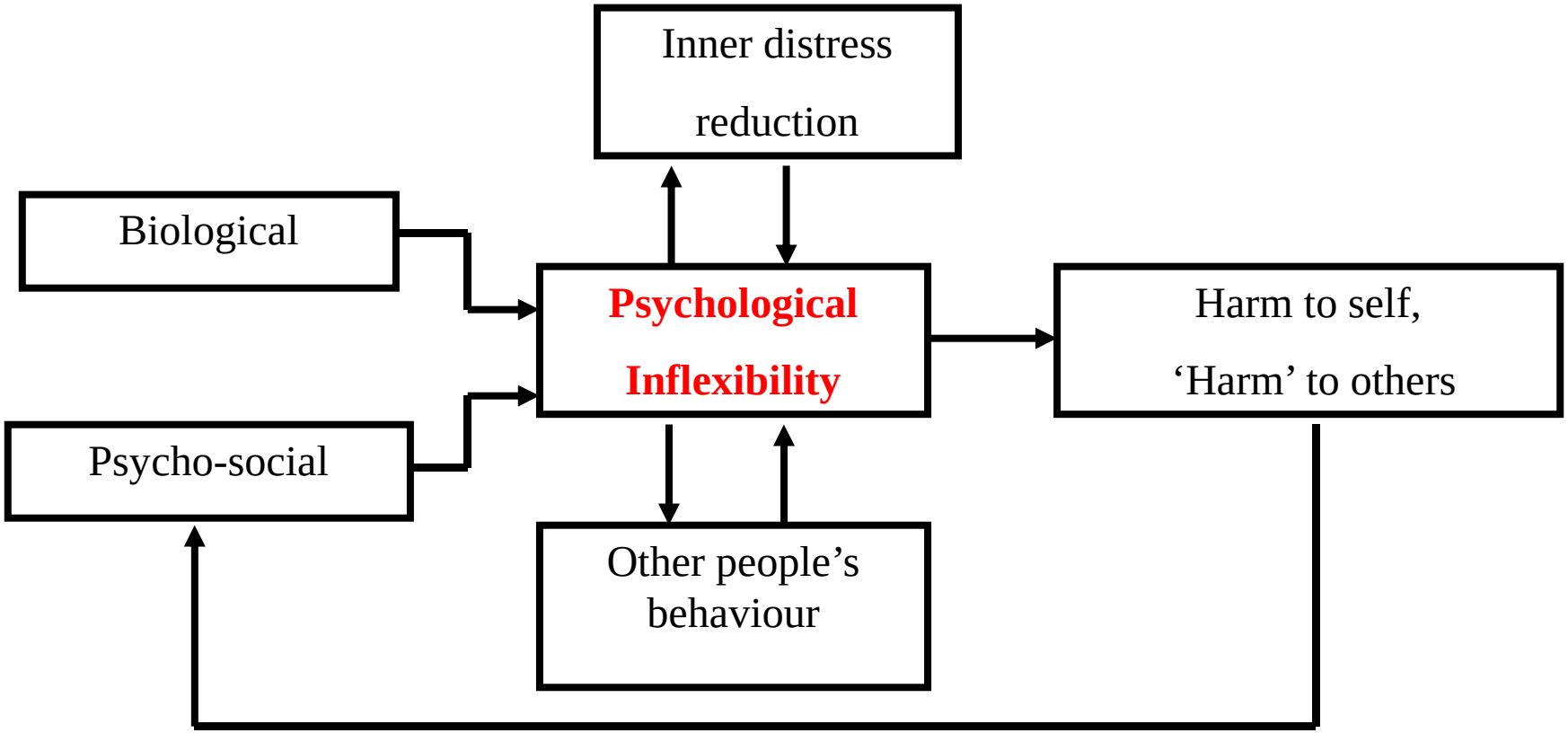
- Shorter meditation exercises
- Eight meditations (less movement, no choice-less awareness)
- Mid-week meeting
- Hand washing/ mindful lunch

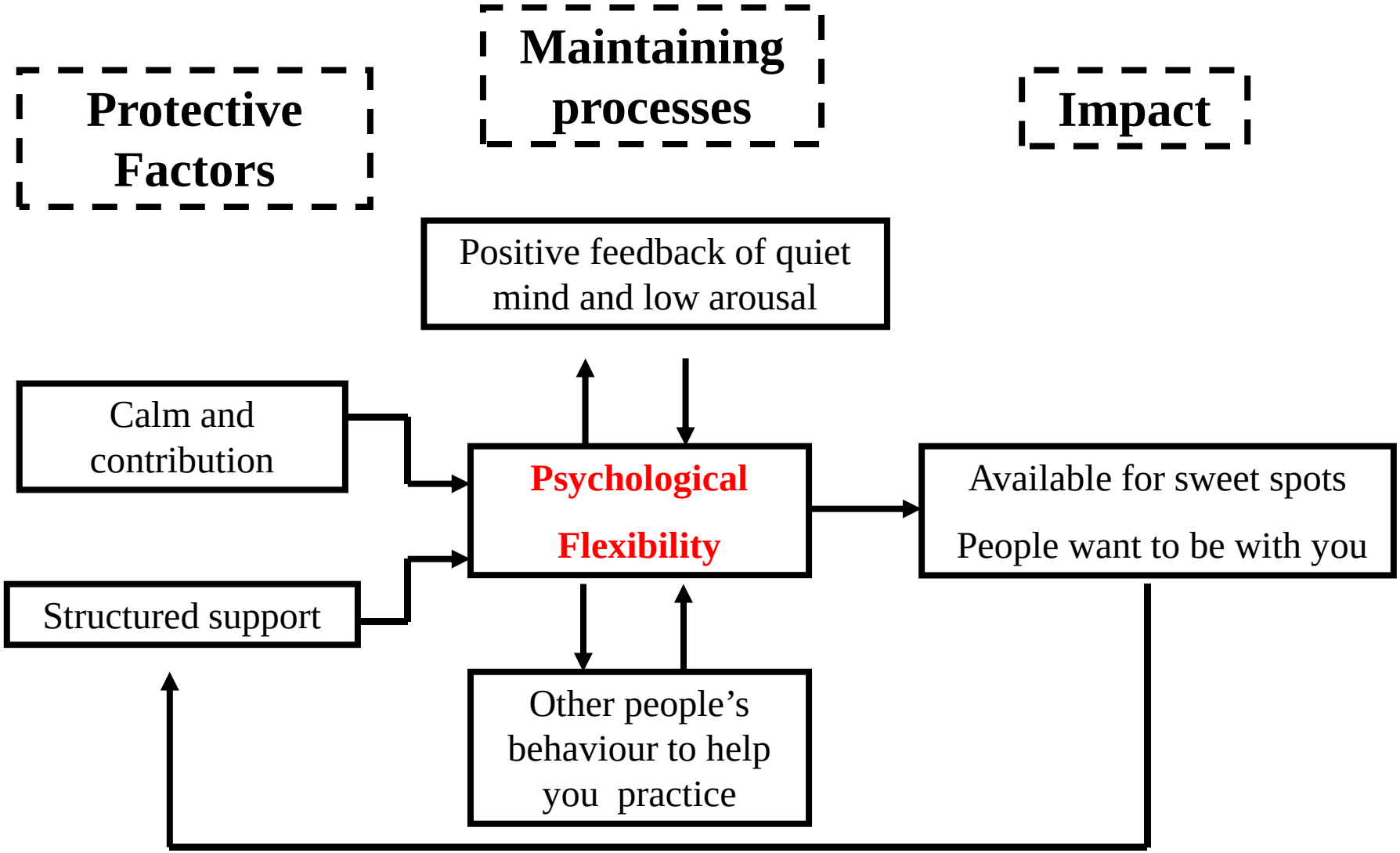

30
25
20
15
10
5
0
Group 1
Group 2
Group 3
Group 4
Started
Completed
Practice Gp

Vulnerabilities

Maintaining processes

Impact




Protective Factors
Maintaining processes
Impact
Positive feedback of quiet mind and low arousal
Calm and contribution
Psychological Flexibility
Available for sweet spots
People want to be with you
Structured support
Other people's behaviour to help you practice

Evaluation

- New verbal repertoire
- Ability to lead a practice
- Practice sessions a way of life
- Reduced self harm and aggressive outbursts
- Increased independence
- Sleeping better
- Reduced Depression

Thank You !

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