Lessons learned from working with ACT with adults with Intellectual Disabilities

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3rd UK & Ireland ACT / Cognitive Behavioural Science Conference
Edinburgh 25th November 2016

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 Difficulties (in UK terminology) is a term 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.

British Dyslexia Association website: www.bdadyslexia.org.uk

ID Criteria

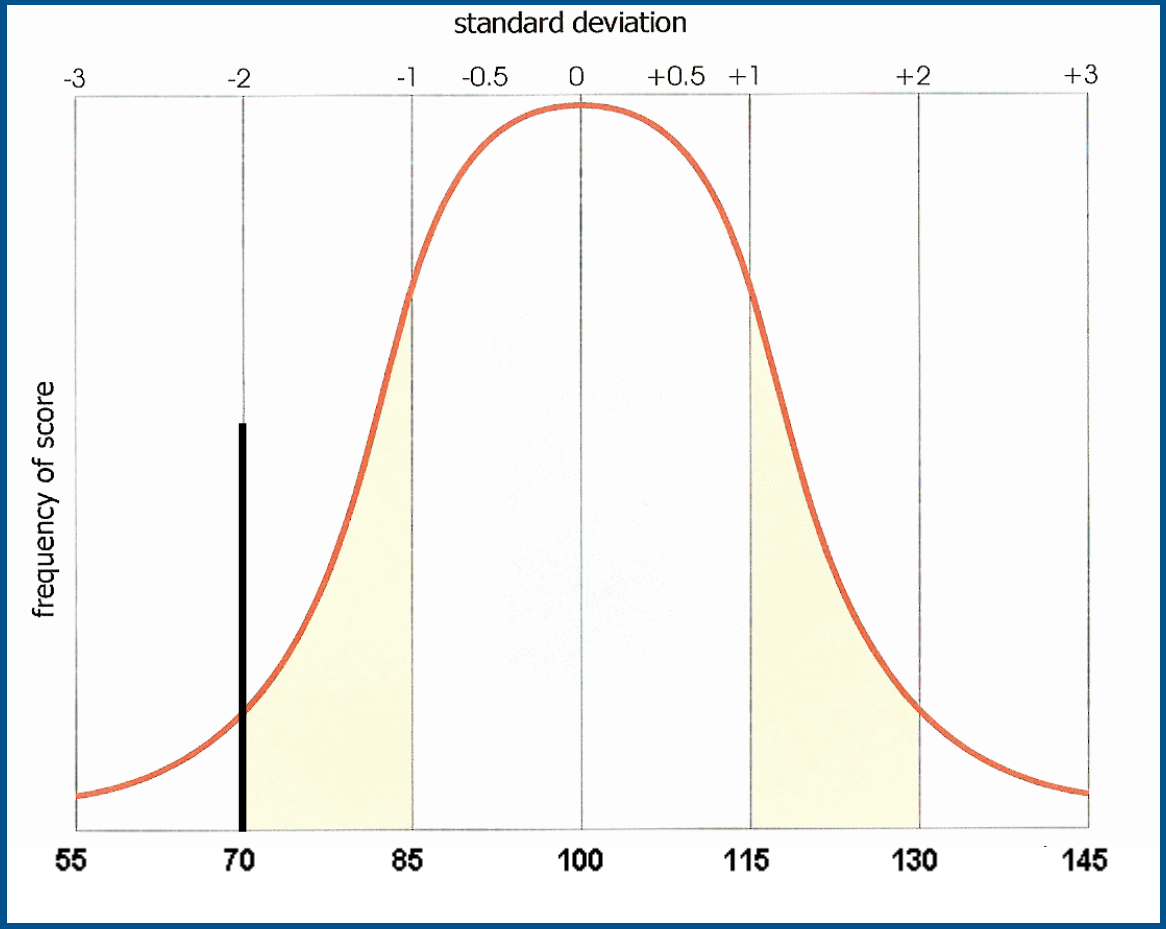
Intellectual Disability is “a condition of arrested or incomplete development of the mind … characterized by impairment of skills manifested during the developmental period which contribute to the overall level of intelligence, i.e cognitive, language, motor and social abilities”. [1]

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 (1)

Mild = 50 - 69

Moderate = 35 - 49

Severe = 20 - 34

Profound = lower than 20

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

Levels of ID (2)

Intellectual Disability = 55 – 69

Severe Intellectual Disability <55

British Psychological Society (BPS). (2015). *Guidance on the Assessment and Diagnosis of Intellectual Disabilities in Adulthood.*

IQ & RFT

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

Studies 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). The Relationship Between Intellectual Functioning and Relational Perspective-Taking. *International Journal of Psychology and Psychological Therapy, 10*(1):1-17.
[2] O'Hora, Pelaez, Barnes-Holmes, Rae, Robinson, & Chaudhary. (2008) Temporal Relations and Intelligence: Correlating Relational Performance with Performance on the WAIS-III. *The Psychological Record, 58*:569-584.
[3] Cassidy, Roche, & Hayes. (2011). A Relational Frame Training Intervention to Raise Intelligence Quotients - A Pilot Study. *The Psychological Record, 61*:173-198.

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.

Within the ACT model, verbal process 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.

ID & ACT - challenges

Attention span likely to be limited

Verbal ability likely to be reduced

Ability to use metaphor likely to be reduced

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

ID & ACT

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).

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

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.

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.

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*.

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.

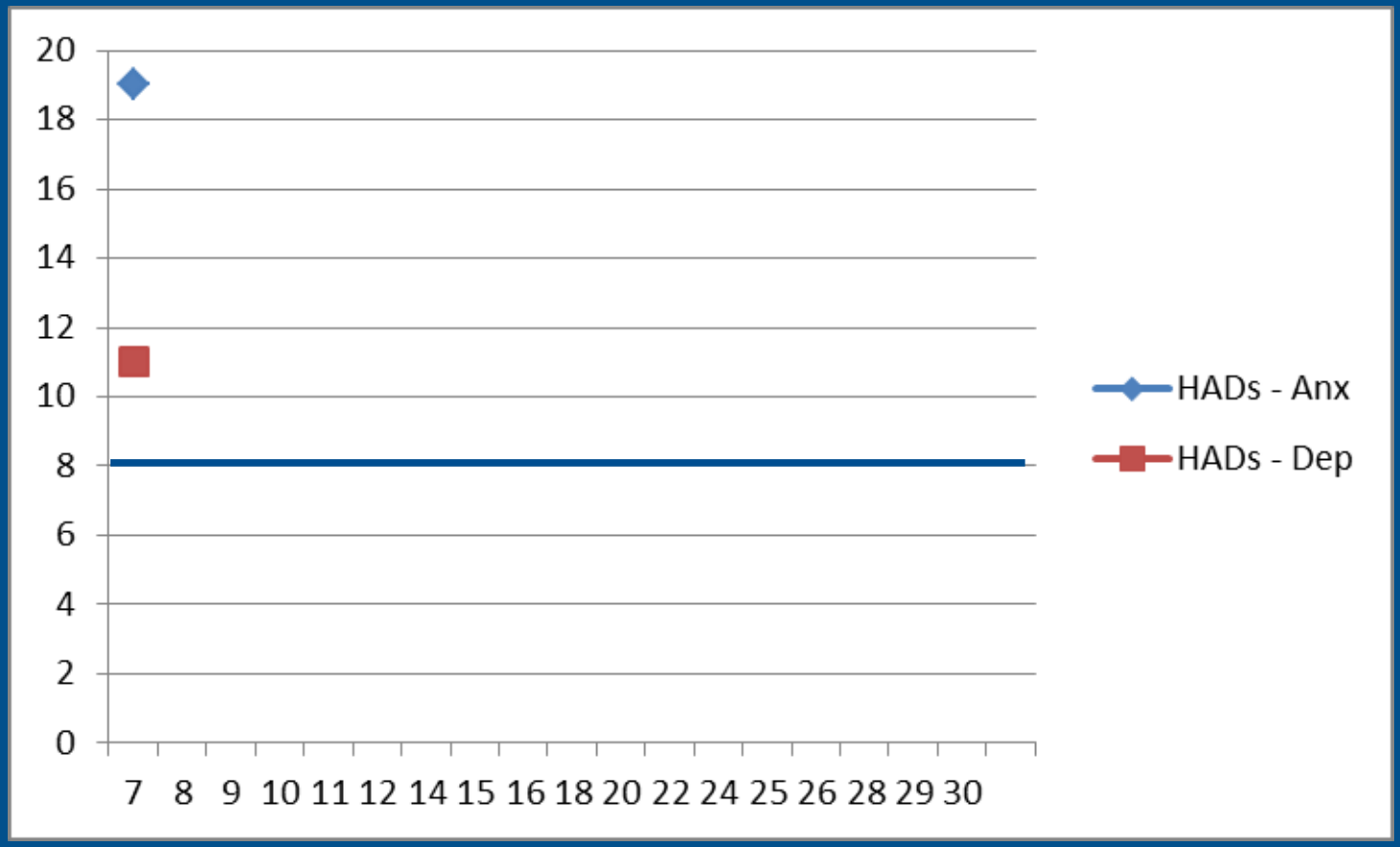
Mild ID and autism.

Living at home with his parents and younger brother.

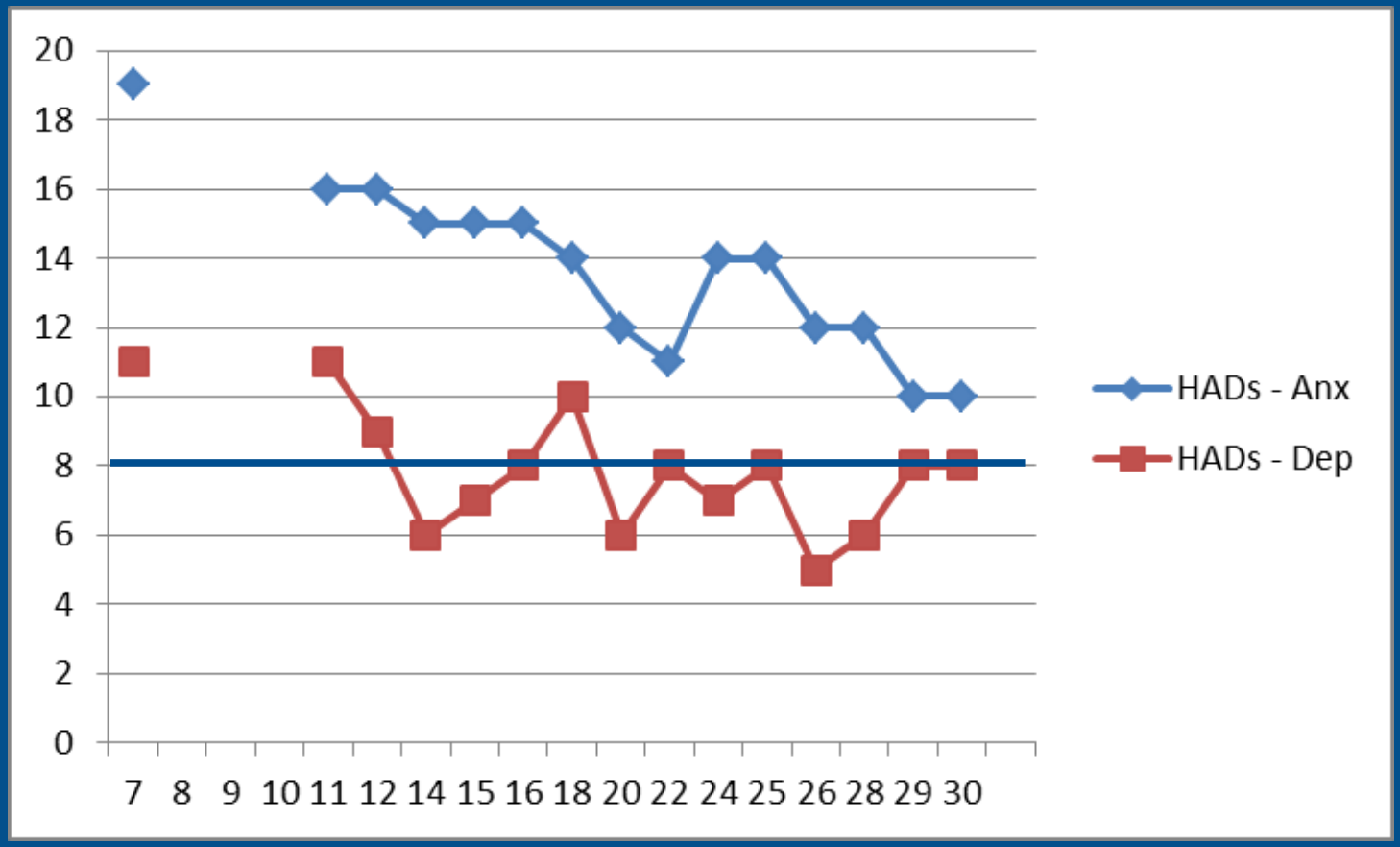
Referred for obsessive thoughts about his family coming to harm. He is restricting their activities to a point where it is causing problems within the relationships.

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

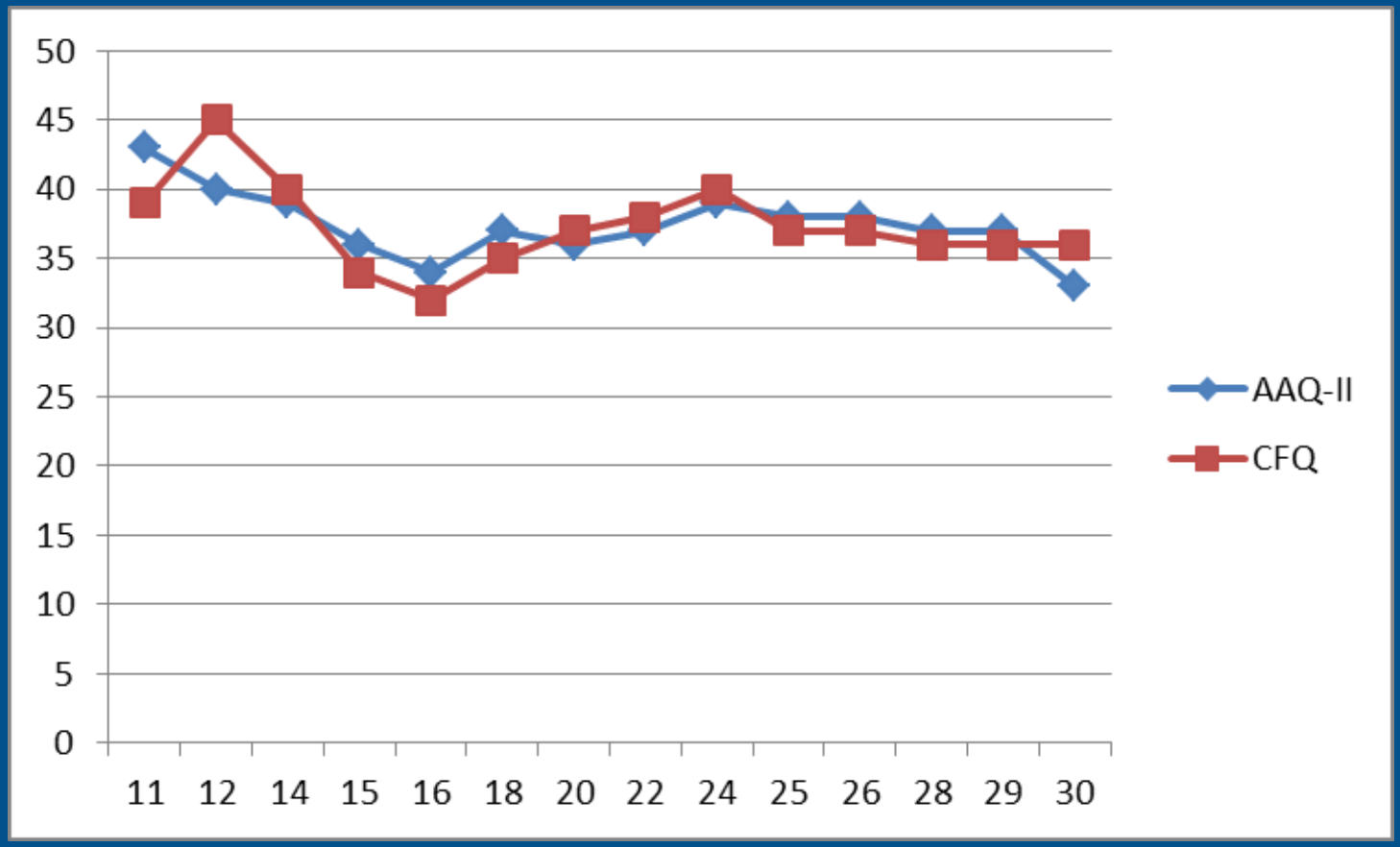
Anxiety and Depression Scores



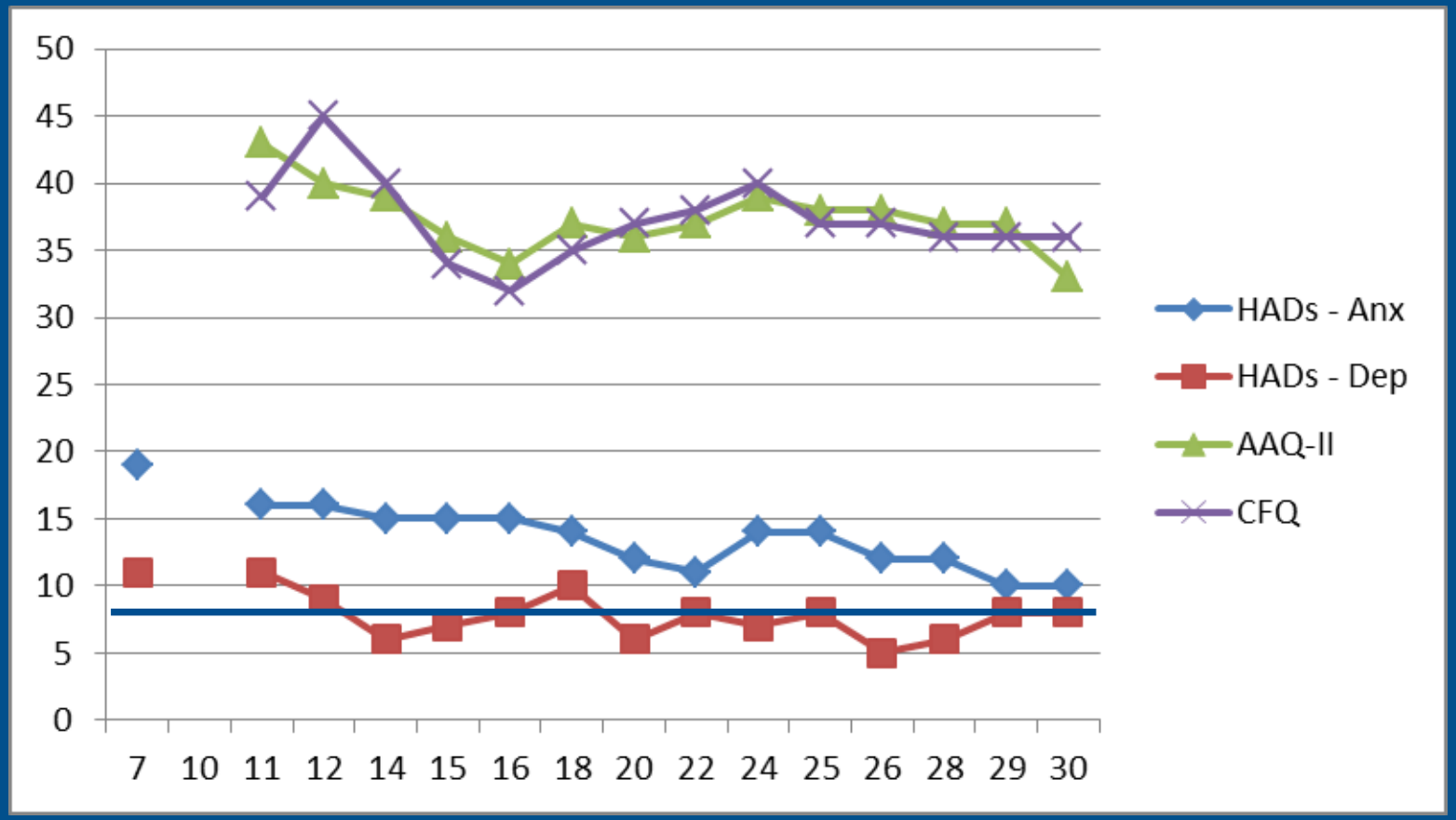
Anxiety and Depression Scores



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.

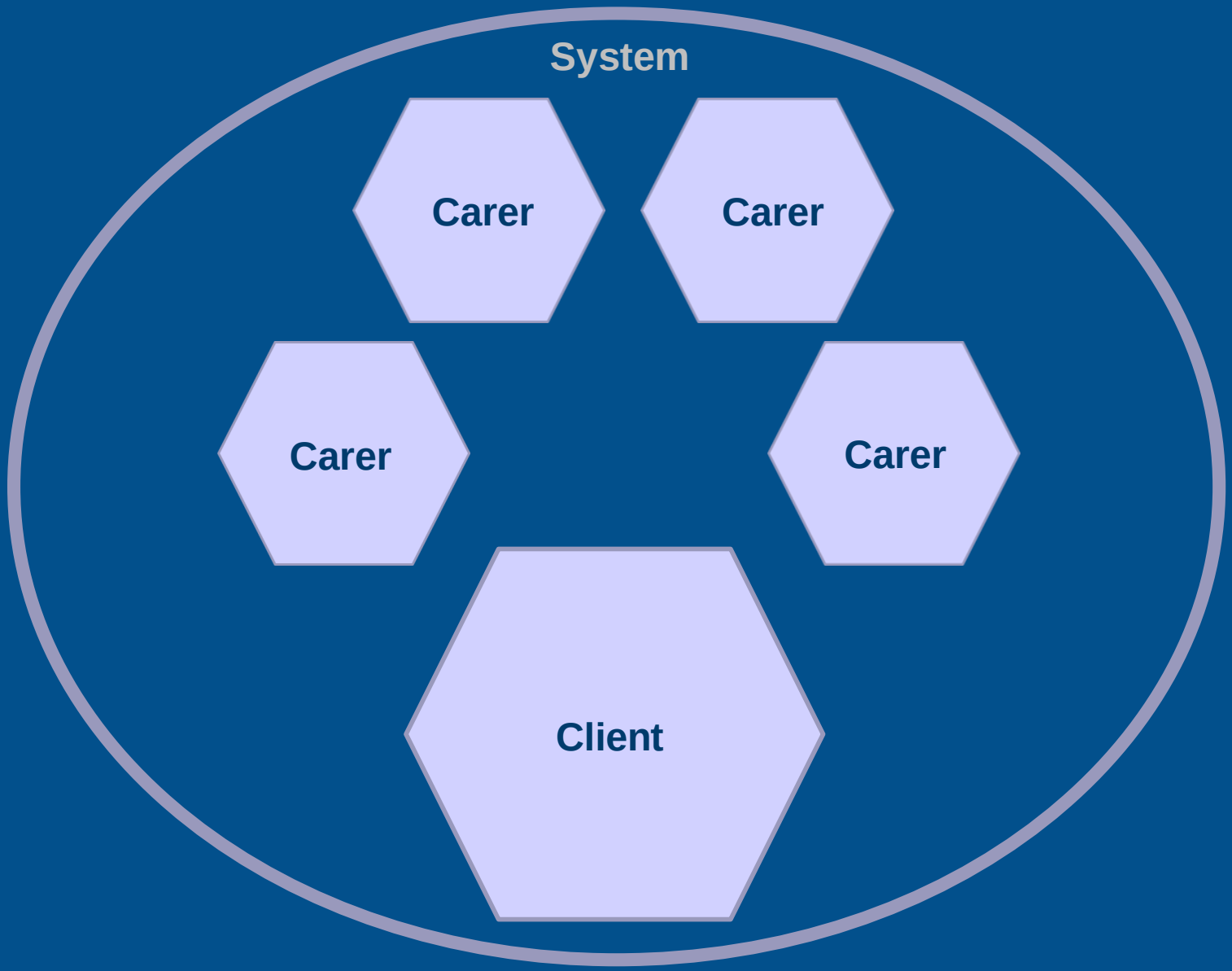
We could do this because Andy had good verbal language skills, but he is at the upper end of ability for our client group.

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

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.

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.

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.

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