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NHS Greater Glasgow and Clyde

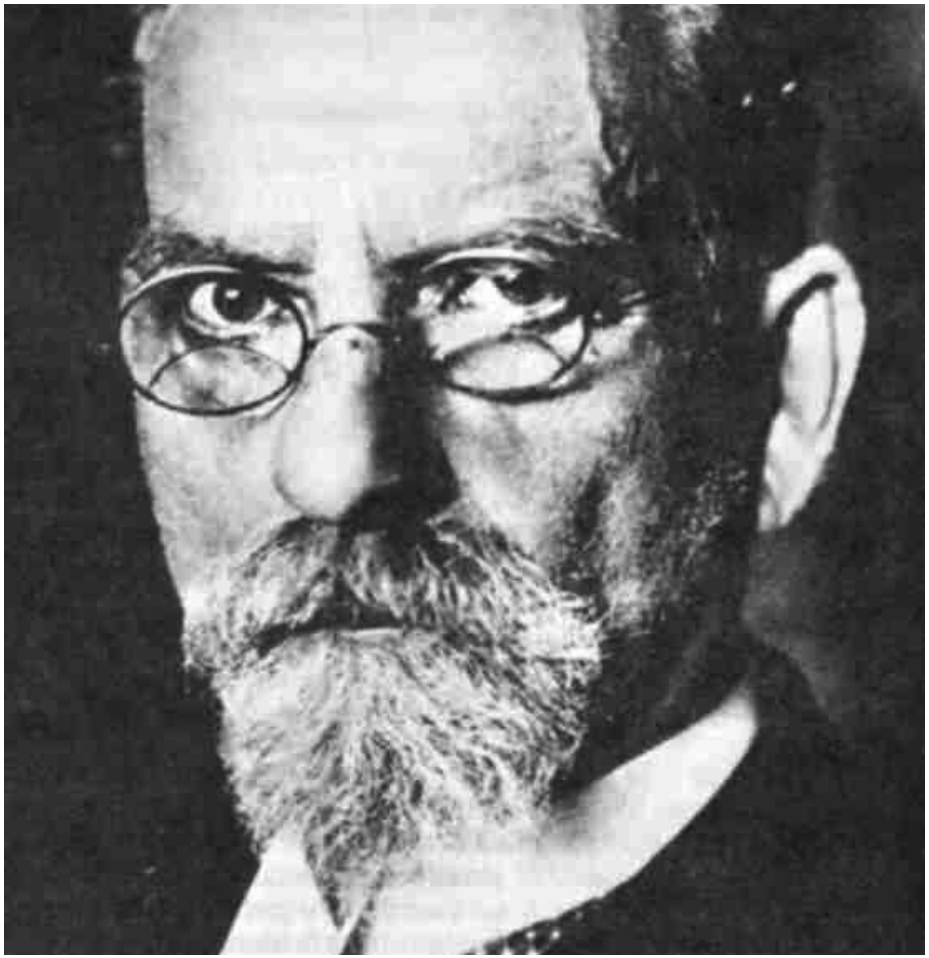
Making a difference: adapting psychosocial interventions for people with Intellectual Disabilities

Structure for today's talk

- **Do diagnoses take account of the experience and context of people's lives?**
- **Life experience and the nature of mental health and inter-personal problems**
- **Some implications for psychological therapy and CBT in particular**
- **How do people with intellectual disabilities view therapy?**
- **Concluding thoughts**

Phenomenology (Edmund Husserl)

- **People's lived experience**
- **How people negotiate their lives as actors in the world**



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DSM-5

Diagnostic and Statistical Manual of Mental Disorders

APA

ICD-11

International Statistical Classification of Diseases and Related Health Problems

WHO

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Controversy

Classification of behaviour and experience in relation to functional psychiatric diagnoses:

Time for a paradigm shift

Criticisms included…

- **Marginalising knowledge from lived experience: Service users often emphasise the primary significance of practical, material, interpersonal and social aspects of their experiences, which only constitute subsidiary or 'trigger' factors in the current system of classification (Beresford, 2013).**

Perhaps linked to phenomenology:

- **How people experience and negotiate their social worlds.**

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Relevance for people with intellectual disabilities

- **Can we assume that depression or psychosis mean the same for someone with a mild or a more severe intellectual disability?**

- **What about behaviour problems? Surely easier to assume that we can look across classes of behavioural difficulties presented by different individuals?**

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Aggression?

Reactive vs Instrumental

Intent to cause harm vs defensive / escape

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Is there a risk we miss something if we don't properly check on people's own experience?

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Phenomenology

Life experience and the nature of mental health and inter-personal problems

Is there something distinct about people's experience / development that we should take into account?

Young people's worries.

An anxious time? Exploring the nature of worries experienced by young people with a mild to moderate intellectual disability as they make the transition to adulthood

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- **Young people with intellectual disabilities (26) and group of typically developing young people (26), aged 16-21.**
- **Groups matched for gender and socio-economic status.**
- **Participants asked about twelve broad areas of worry, taken from themes highlighted in previous research with adolescents.**
- **Visual stimuli used to illustrate the different kinds of worry. After talking about the worries evoked by the stimuli, participants were asked to rank their main four worries.**

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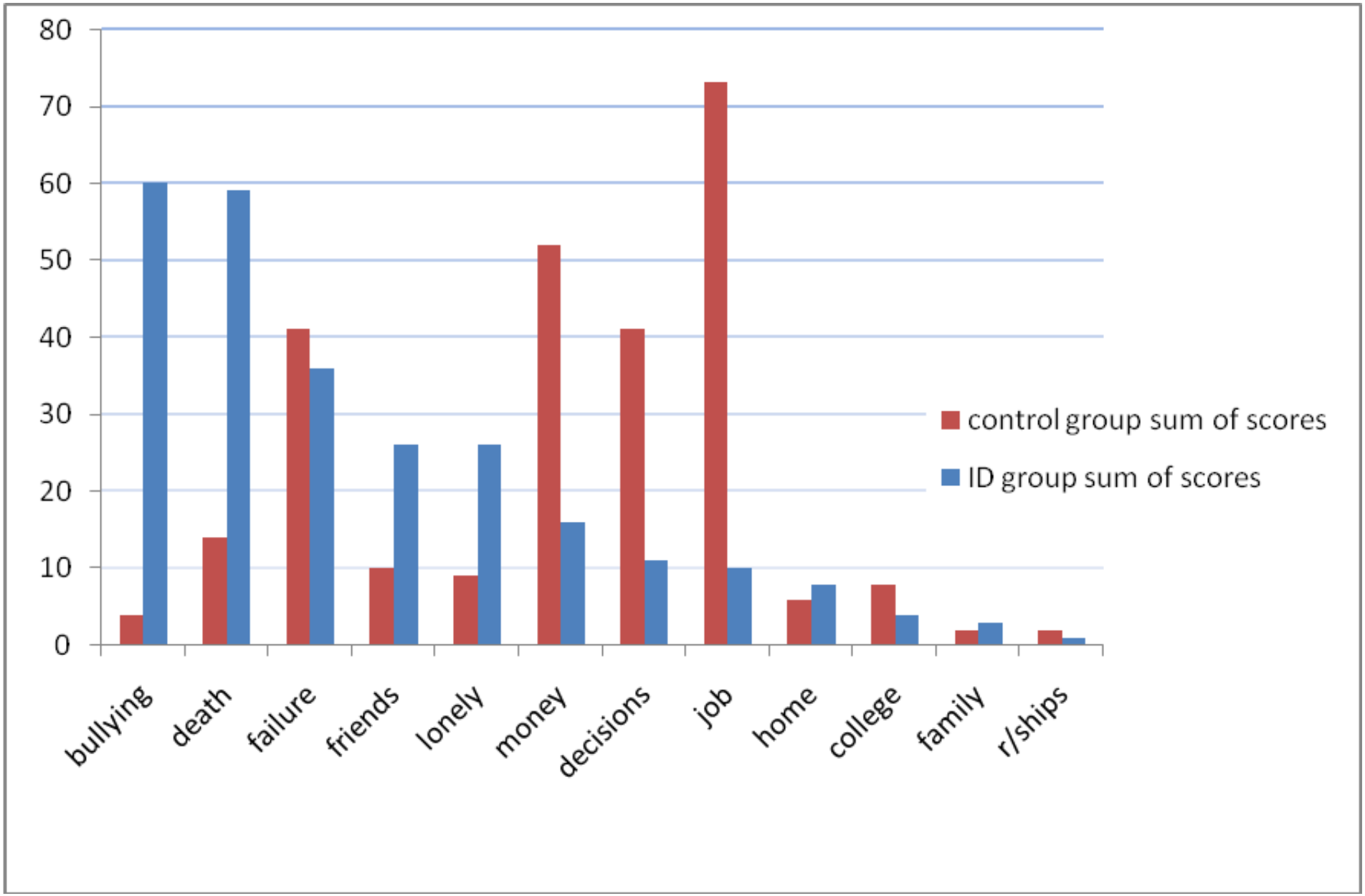


Different kinds of worry.

- **The two groups generated different kinds of worry.**
- **The only overlap was in terms of failure, and even then the nature of the two groups' worries in this regard were rather different.**
- **While the non-disabled group talked about specific failures and their implications (driving test, school exam), those with intellectual disablities talked about a general sense of incompetence.**

  I feel like a failure all the time, it's just like the useless thing again in a way, because I can't get college right, I can't get friends right…I want to join clubs but it's like friends, are they going to judge me for how I am so it's the same kind of roller coaster up here and down there, will I fail?

Group differences

Young people with intellectual disabilities:

- **ruminated more about their worries [t(34.95)=2.34,p=0.025].**
- **were significantly more distressed by their worries [t(50)=4.96,p<0.001].**
- **had significantly higher self-report anxiety scores between groups [t(50)=2.247,p=0.029].**
- **had significantly lower self-efficacy scores than the typically developing young people [t(50)=2.79,p=0.008].**

What does this tell us?

- **People's worries seem to reflect a history of dealing with adversity and their particular social circumstances.**
- **We do not know if such worries increase vulnerability to future mental health problems, but the higher levels of distress and rumination might be negative signs.**
- **Perhaps we look for major life events with people who have intellectual disabilities and sometimes overlook the corrosive effects of more mundane experience.**

The emotional challenges of negotiating everyday life.

Frequent inter-personal aggression

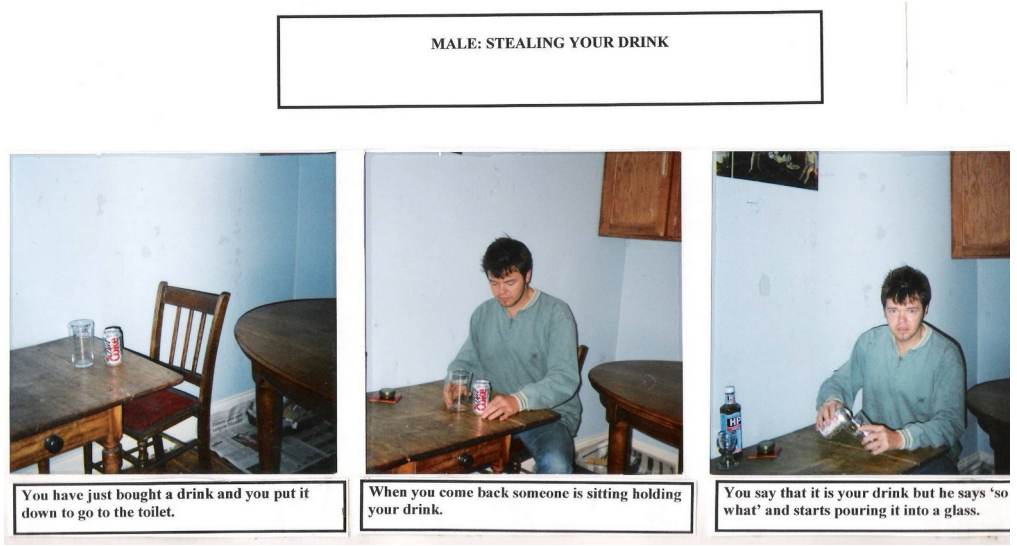
Who are you looking at?

Submission and aggressiveness.

- **In this study we looked at how people with significant problems of aggression (18) view both aggressive and submissive behaviour, as compared to nonaggressive peers (18).**

- **We wanted to find out what the participants thought the outcomes of behaving both aggressively and submissively in situations of potential conflict might be.**

- **Presented with vignettes and asked to imagine themselves as the protagonists in the stories where they faced potential conflict and responded i) aggressively, and ii) submissively**



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Participants' positive views of aggressive and submissive behaviour.

Inter-personal aggression in context

- **The participants who had problems with frequent inter-personal aggression were more likely to endorse aggressive responses to potential conflict and to find submissive responses intolerable**

- **How people view themselves in relation to others helps to determine their reactions.**

- **Whether or not emotional regulation or other particular social cognitive deficits play a part in people's aggressiveness, the difficulties are enacted in a social context.**

What about psycho-social therapies?

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Cognitive Behavioural Therapy – an example

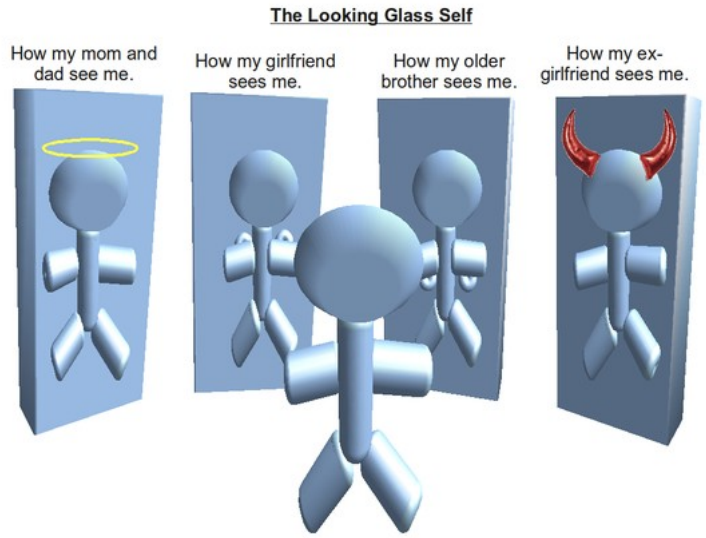
- **Not just about adapting the technique to make it more accessible also about the content**
- **It means asking the right questions. For example, acknowledging the potential impact of stigma or social exclusion and perhaps acknowledging difficulties relating to someone's disability**
- **It means <u>not</u> challenging people's views that are based in reality**
- **It may mean working with people's sense of self**

Involve significant others in therapy

Why?

- **People lack power to generalise therapeutic achievements into their everyday lives**

- **A reflected self – not just thinking and behaving in ways that cause less distress but also how seen and treated by others**



Zone of proximal development: learning in collaboration.

- **Vygotsky's concept of the 'zone of proximal development' has been used to describe how to work effectively with people who have psychosis**
- **Not too difficult to easy**
- **The idea that the therapist is trying to provide scaffolding to help the person achieve change that would otherwise be beyond their reach is helpful**

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A Video Review Study

What do people with intellectual disabilities make of therapeutic interventions?

Do video reviews of therapy sessions help people with mild intellectual disabilities describe their perceptions of cognitive behaviour therapy?

B. Burford & A. Jahoda

Academic Unit for Mental Health and Wellbeing, Glasgow University, Glasgow, UK

Participants who took part in a video review of CBT sessions they had taken part in

- **18 clients took part (9 women and 9 men).**
- **Participants referred to clinical psychologists with a range of emotional problems: anger, anxiety and depression.**

Do video reviews of therapy sessions help people with mild intellectual disabilities describe their perceptions of cognitive behaviour therapy?

B. Burford & A. Jahoda

Academic Unit for Mental Health and Wellbeing, Glasgow University, Glasgow, UK

Video review study - a qualitative approach.

Video review method.

Part of a larger process study, Jahoda et al., (2009).

- **6 experienced therapists (Clinical Psychologists).**
- **Individual formulation driven approach. Fidelity checks carried out by CBT expert.**

Aims

- **To look at clients own experiences of CBT sessions.**
- **Pilot the video review method with this client group.**

Method and Analysis

- **Video Review Method devised by Bronwen Burford (2003).**
- **Clients view tapes of therapy sessions and comment on what they see.**
- **Important that clients were NOT confined by specific questions set by the researcher.**
- **No ‘right or wrong’ response.**

Analysis

Data analysed using Thematic Analysis

Why bother? Because….

Two main strands to the findings.

1. Supportive aspects of therapy

- Valuing a positive therapeutic relationship.
- Feeling supported and understood.
- Valuing the chance to talk about feelings.

2. Changes linked with a CBT approach.

- Working together on problems. CBT approach leads to better understanding of problems and better coping skills.
- Positive impact on self identity and self efficacy.

FINDINGS. What clients say about CBT (1)

A positive therapeutic alliance.

"I've never ever told anybody else, I wanted to talk about that. I feel really, really glad with (T). It felt really good, I trust (T).

Trust

Empathy

" I enjoy the sessions with (T), they're good. And I felt that (T) understands how I feel. More or less that I've got feelings."

(T is the therapist)

What clients say about CBT (3).

Learning about myself.

"Never heard myself say that before. Never done in my life. I've always hurt people and caused grief. I'm seeing a different me"

Views of self.

"When I was watching myself I was thinking is there anything wrong with me or not? People say there is and I say there's not. But when you see that I don't know what to think."

What clients say about CBT (2).

Talking about problems is helpful.

"T's good to talk to and that's helpful. I come here to get a bit of help.".

Enjoy talking

Having someone to talk to.

"…..It's kind of helped me cope with life. Because before (T), before I came here I'd actually nobody to talk to really."

BUT: Change can be seen as fragile

- **Change might not last.**

'I just don't want to stop seeing (therapist) because it'll take some time to get to see her again…'

Cognitive behavioural therapy from the perspective of clients with mild intellectual disabilities: a qualitative investigation of process issues

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Making a real difference

A tension

Private space  **Life in context**

CBT and real life change

- **Behavioural activation for depression**
- **Increasing purposeful and meaningful activity, overcoming withdrawal and bringing people in contact with more reinforcing aspects of life**
- **Key adaptations: the involvement of a significant other and the attempt to make it the beginning of a new pattern of life rather than an endpoint**

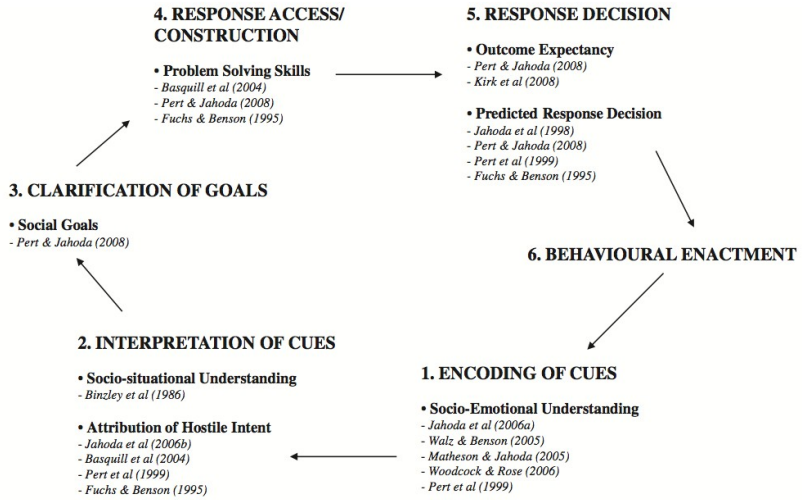
Concluding thoughts

- **Ensure psychosocial interventions remain just that**
- **About working with the whole person in the context of their lives – not a disease entity separate from the person**
- **Aim to achieve change that makes a real difference to people's lives**
- **Health promotion as well as dealing with mental ill health building on people's strengths**

Concluding thoughts

Adapting interventions:

- Still a tendency to fall back on cognitive deficit models, rather than considering cognitive content.
- BUT NOT NECESSARILY ONE THING OR ANOTHER
- We still need to consider how people's intellectual difficulties might interact with their emotional experience.



Concluding thoughts

- **Research on underlying psycho-social factors that contribute to emotional distress or make change difficult**

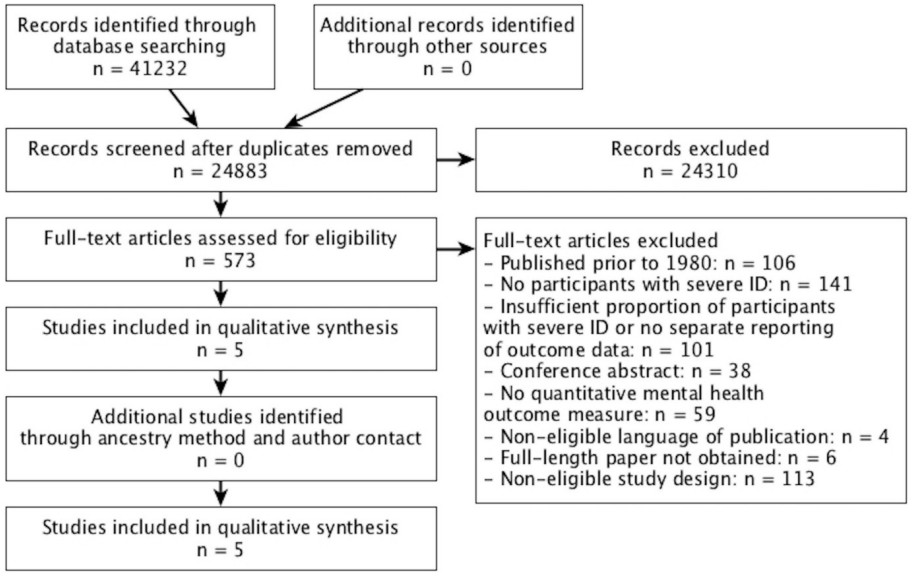
- **An engagement with research on process of therapeutic change and also on maintaining change**

Not everyone is included…

BMJ Open

Interventions for mental health problems in children and adults with severe intellectual disabilities: a systematic review

Leen Vereenooghe,[1] Samantha Flynn,[2] Richard P Hastings,[2,3] Dawn Adams,[4] Umesh Chauhan,[5] Sally-Ann Cooper,[6] Nick Gore,[7] Chris Hatton,[8] Kerry Hood,[9] Andrew Jahoda,[6] Peter E Langdon,[7] Rachel McNamara,[9] Chris Oliver,[10] Ashok Roy,[11] Vasiliki Totsika,[3,12] Jane Waite[13]



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Thank you!