

# Developmental Trauma and Intellectual Disability: A question of causality

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# Aims of the presentation

- o To offer ours, and colleagues, reflections of 20+ years of experience of working with people with Intellectual Disabilities who have also been exposed to significant trauma in childhood
- o To encourage debate about the factors that underpin lower than average levels of functioning
- o To explore the construct validity of formulating early and prolonged developmental trauma as an intellectual disability
- o To explore what would be the practice implications and guidance for reformulating need within a trauma framework



# Before we start...

We are **NOT** suggesting that:

- o All learning disabilities are caused by abuse, neglect or poverty
- o Promoting a purely medical / diagnostic model

We **are** encouraging debate focusing on

- o the needs of people with 'Mild' Intellectual Disabilities (mID) and borderline intellectual functioning (BIF)
- o Stressing that cognitive functions are underpinned, in part, by biological process
- o A small subset of this group who have been exposed to prolonged and significant periods of trauma

# The role and function of diagnostic systems



- To inform our understanding of prognosis and treatment plans for individuals presenting with clinically unified [similar] patterns of symptoms. They comprise of a series of shared symptoms and diagnostic criteria, which should also have clinical utility (APA, 2013).
- Diagnoses are based on the assumption that that clusters of symptoms have:
  - **Pathogenesis:** Common biological mechanism (chain of events) that leads to a diseased state or its development
  - **Pathobiology:** Underpinned by the same biological processes
  - **Course:** How presentation changes over time: Sequence, pace and stages of presenting needs and symptoms
  - **BUT:** Syndrome's can have diverse causes if they have shared pathobiology or pathogenesis; as the classification of syndromes and disorders is based on shared signs and symptoms, not causes (Rush & Ibrahim, 2018).
- Diagnostic criteria are offered as 'guidance' to clinicians and should be considered and informed by clinical judgement (APA, 2013).

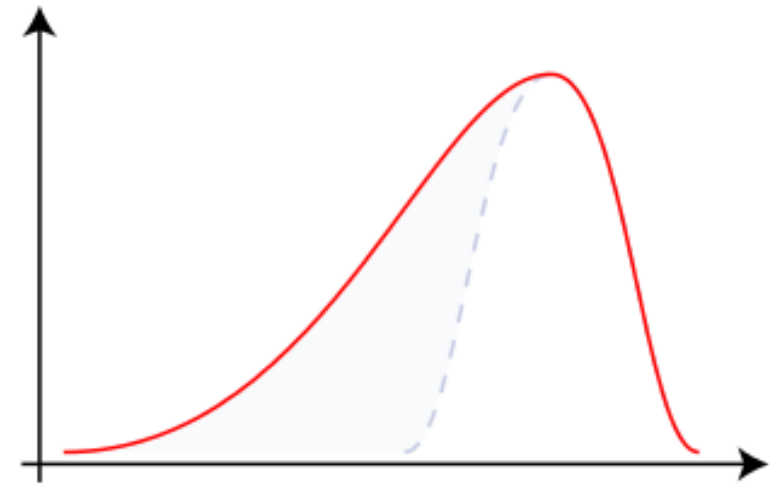
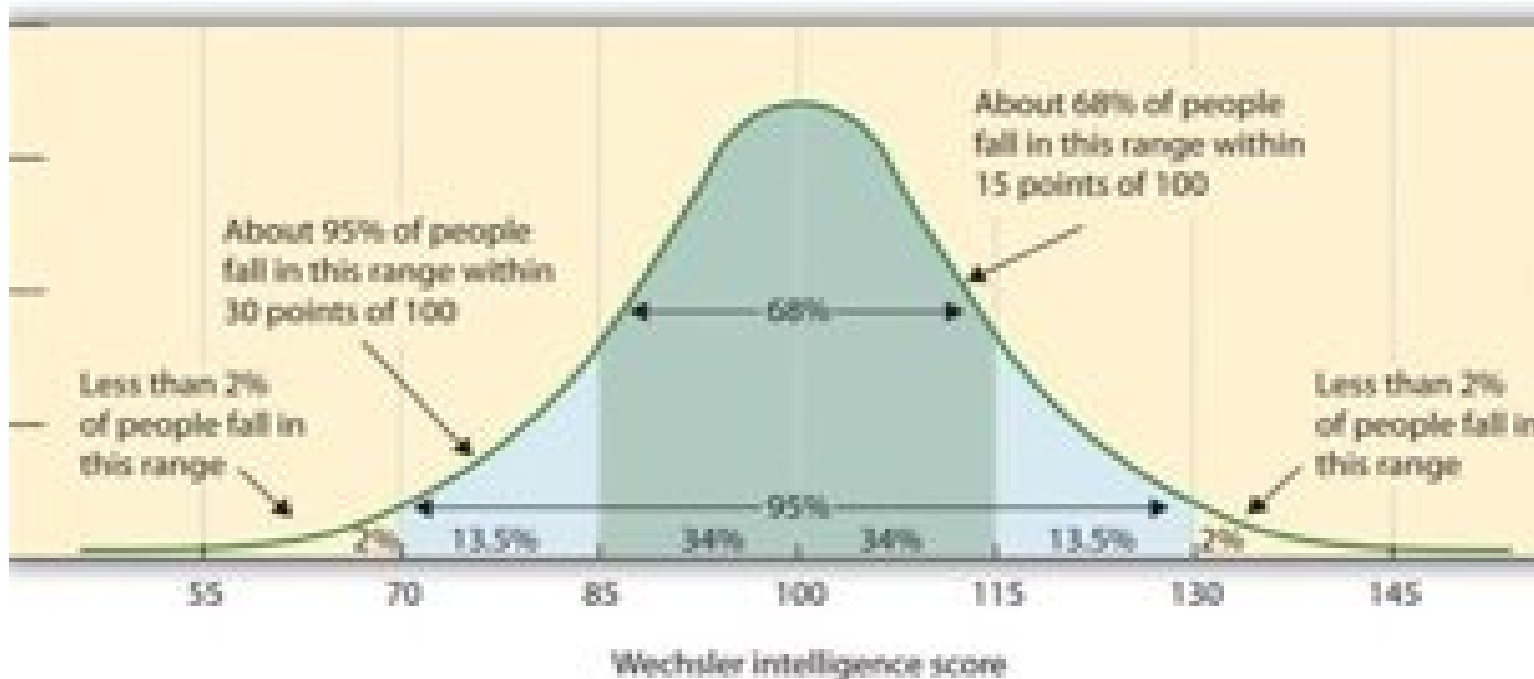


# Intellectual Disability Diagnosis: ICD-10

- *“A group of etiologically diverse conditions originating during the developmental period characterized by significantly below average intellectual functioning and adaptive behavior that are approximately two or more standard deviations below the mean (approximately less than the 2.3rd percentile), based on appropriately normed, individually administered standardized tests. Where appropriately normed and standardized tests are not available, diagnosis of disorders of intellectual development requires greater reliance on clinical judgment based on appropriate assessment of comparable behavioural indicators.”*
- *Key Features:*
  - *Emerge during developmental periods*
  - *Below average intellectual and adaptive behaviour*
  - *Two or more standard deviations below the mean....*
- *NB: No consideration given to the aetiology / cause of deficits*

# Common concerns about ID diagnoses

- There are continued debates relating at a conceptual and practical level relating to diagnostic nosology of intellectual disability (Felstrom et al., 2005; Salvador-Carulla et al., 2011).
- It is acknowledged that ID's are often misdiagnosed (Salvador-Carulla et al., 2011)
- Over reliance on IQ scores (which ICD-11 attempts to rectify)
- Psychological Impact of the diagnosis (stigma)
- More recently questions about the use of this framework for describing the needs of people, which stem from significant periods of neglect and abuse



# Assumptions and implications of Intellectual Disability Diagnoses

- Assumption that deficits are present before or at birth unless a brain injury is acquired in the developmental period (before 18 years)
- Assumption of permanence or irreversibility of level of cognitive functioning and disability
- Concept of maximizing capabilities rather than enhancing (can't 'cure' an intellectual disability)
- Life-long



# The aetiology of Intellectual Disabilities

ID's represent an etiologically diverse set of conditions that can have multifactorial and often undetermined aetiologies.

## Centre for Disease Control (CDC)

Genetic factors (17-50% of ID's; Karam et al., 2015)

Infection: Prior to, at birth or following birth

Chromosomal abnormalities

Metabolic, e.g. hyperbilirubinemia

Toxic (substance and environmental)

*Nutritional*

1 in 4 IDs, across levels of severity are of 'unknown cause'

## Mild ID

50% of mID having an unidentified cause(Yaqoob, 2004)

1/3 of cases of mild intellectual disability have been attributable to post-natal factors, of which social deprivation and malnutrition were the identified as the causes

? The role of chronic exposure to adversity?



Intellectual Disabilities and  
early exposure to adversity

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# The role poverty, neglect and abuse in the aetiology of Mild Intellectual Disabilities and Borderline Intellectual Functioning

- People with intellectual disabilities are significantly overrepresented in all categories of early adversity and harm in all categories of home, community and institutional abuse
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- **Home**

- Neglect & abuse
- Witnessing, violence familial substance use and mental health difficulties
- Being removed from the home

- **Institutional**

- Multiple Placements (inc breakdowns)
- Care giver instability
- Greater difficulty in securing long term placements
- Being placed in non-specialist generic mental health inpatient services

- **Community**

- Disruptions to education
- Bullying

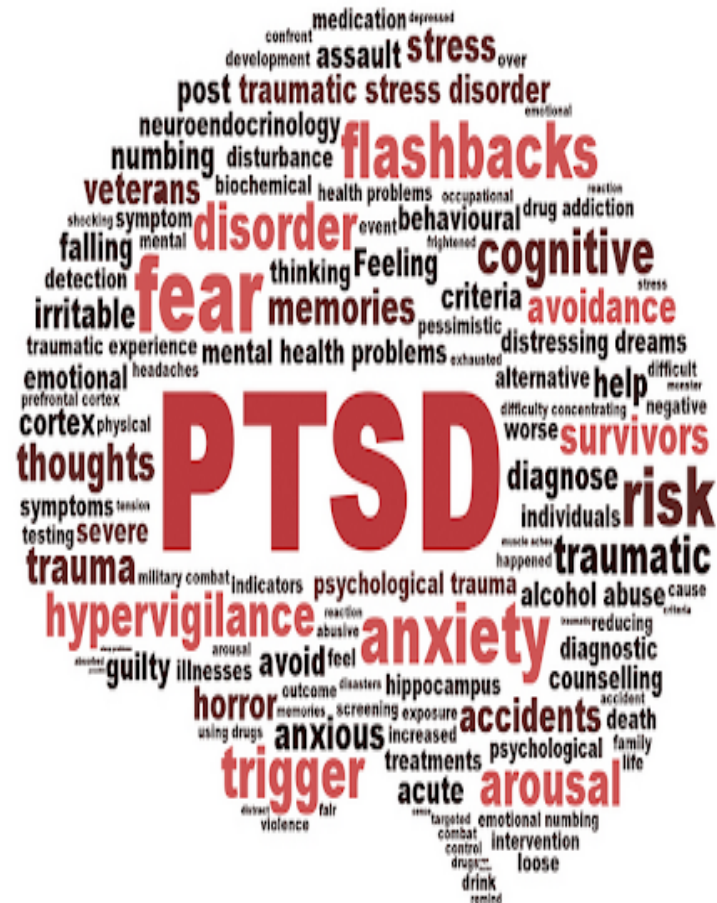
# Prevalence of trauma symptomatology in intellectual disability and borderline intellectual Disability

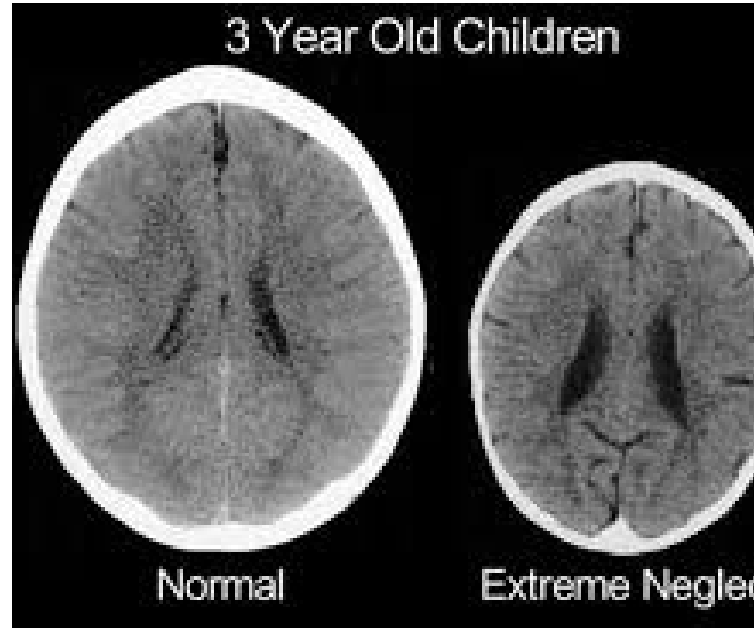
## Borderline ID

- post traumatic stress, 2nd most common psychopathology reported (Pena-Salazar et al., 2018) (role of education as a protective factor)
- Children higher vulnerability to develop PTSD than neurotypical controls (Finzi-Dottan et al., 2006; Weiss et al.,)

## Mild – Moderate ID

- Difficulties in identifying core symptoms of PTSD (reexperiencing and avoidance) Kildahl et al. 2019
- Responses to trauma may be mediated by developmental level (Wigham et al., 2011)
- Morris et al., 2020 (N=123) 58 (47%) met criteria for PTSD and 80 (65%) met criteria for DTD in adults in secure care
- BUT:** Psychological aspects of trauma represent only one aspect of the impact of trauma and there are risks to 'reducing' the impact of prolonged exposure to abuse / neglect under to psychological manifestations under the umbrella of PTSD





The impact of trauma on global development:  
Can early trauma significantly lower IQ and  
functioning and mirror the needs of those with  
intellectual disabilities?

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# Can early trauma lower IQ & functioning?

## Impact on neurological functioning

- Smaller whole brain, smaller and dysregulated functioning in key areas of the brain
- Neurochemical changes
- Truncated and incomplete growth in key areas of the brain associated with emotional regulation, cognitive functioning and social processing skills

## Impact on neurological resources associated with IQ

- Memory, executive functioning :planning, organizing, sustaining, problem solving & flexibility, attentional skills



## Impact on educational progress

ACEs associated with school attainment at KS1 & KS2 (Evans et al., 2020 N over 100,000: Controlled for confounding variables, school, economic, perinatal)

8 FSIQ point difference witnessing prolonged Intimate Partner Violence (Koenen et al., 2003)

## Impact on functional skills and

- Greater risk of expulsion from school, poorer attainment and fewer qualifications
- Increased unemployment and lower income
- Higher levels of disability benefit and living below the poverty level



# Key Concept: Neuroplasticity

Can the brain 're cover' or re wire itself following prolonged exposure to early trauma? If yes – is this further evidence to differentiate the two populations

## **Psychological trauma within ID populations**

Case study series evidence of significant improvements on WAIS-IV subtests following DBT in non-verbal reasoning, working memory & Processing speed and FSIQ M=9 (5-20) points (Morris & Beber, 2015)

## **Romanian orphan studies: Deficits and improvements in functioning** ***Rutter (various)***

Children who experienced severe neglect presented with symptoms consistent with ADHD, including similar deficits on cognitive functioning but could be differentiated from 'ADHD' over a period of time suggesting that differentiating between ACEs from other ID's is possible

## ***Nelson et al.*, BEIP (Bucharest Early Intervention Programme: RCT)**

Romanian children Foster care vs institutional care (and community control)

Foster vs remaining in institutional care

- Significant improvements in secure attachment (49% vs 18%)
- Significant improvements in FSIQ 81 vs 73
- Fewer emotional disorders



## Key Concept: Neuroplasticity (2)

### **Mindfulness and improvements in neurological functioning**

Systematic reviews of fMRI studies in relation to the impact of Mindfulness on multiple mental health and neurological disorders suggest significant improvements in structure and functioning in areas of the brain associated with trauma

- Psychosis
  - Bipolar
  - Migraine
  - Parkinsons
- 
- **Acquired Brain Injury (ABI) in childhood**
  - Prognosis and improvement is in part dependant on the location of the injury  
But
  - the development of new neural networks is possible
  - The brain can 're learn'
  - Early intervention is key

# Revisiting Pathogenesis, pathobiology and course

|              | Intellectual Disabilities                                                                                                                                                                                                                                                                                                                          | Early Trauma<br>(during developmentally sensitive periods)                                                                                                                                                                               |
|--------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Pathogenesis | <ul style="list-style-type: none"> <li>Genetic factors</li> <li>Infection: Prior to, at birth or following birth</li> <li>Chromosomal abnormalities</li> <li>Metabolic, e.g. hyperbilirubinemia</li> <li>Toxic (substance and environmental)</li> <li>Nutritional</li> <li>1 in 4 IDs, across levels of severity are of 'unknown cause'</li> </ul> | <ul style="list-style-type: none"> <li>Epigenetic pathways</li> <li>Neglect</li> <li>Abuse</li> <li>Witnessing violence</li> <li>Exposure to substance use, mental illness, prison</li> <li>Significant care giver disruption</li> </ul> |
| Pathobiology | Neurobiological                                                                                                                                                                                                                                                                                                                                    | Neurobiological (?? Greater neuroplasticity??)                                                                                                                                                                                           |
| Course       | <ul style="list-style-type: none"> <li>Life long</li> <li>Shorter life expectancy</li> </ul>                                                                                                                                                                                                                                                       | <ul style="list-style-type: none"> <li>Life long, though potential for a degree of recovery in cognitive, attachment &amp; social skills recovery</li> <li>Shorter life expectancy</li> </ul>                                            |

# Key Question

Should a brain and associated cognitive functioning that has been 'rewired' through abuse and trauma, be considered the same as an intellectual disability?

# Alternative Paradigms

## Developmental Trauma Disorder

Proposed originally by (van der Kolk) and updates by Ford (various), Ford, Spinazzola et al., 2018

15 symptoms across 3 symptom clusters, which mirror those of cPTSD and ID

- (1) **Emotion and somatic dysregulation:** including impaired access to and verbal mediation of emotional and somatic feelings)
- (2) **Cognition and behavioural dysregulation:** attentional bias towards or away from threat object, impaired self-protection and self-soothing behaviours, impaired goal initiation and sustaining behaviours non suicidal self-harm
- (3) **Self and relationship dysregulation:** self-loathing and disordered attachment, reactive verbal and physical aggression, betrayed based schema systems, impaired psychological boundaries and interpersonal empathy)





# The evidence base: Developmental Trauma (disorder)

At a conceptual level an international survey of clinicians supported DTD being of comparable clinical utility to PTSD, was not fully accountable by other disorders, and was not treatable with current evidence-based, psychotherapeutic treatment approaches (Ford et al., 2013)

Studies have also reported support for DTD as a construct with children who met criterion A (exposure to ACEs) being significantly more likely than those who were not, to meet DTD criteria, suggesting support for the discriminant validity of the diagnosis (Stolbach, et al., 2013).

DTD also appears to have similarities and distinctions from PTSD, suggesting it makes a unique contribution to our understanding of the trauma needs of those exposed to ACEs (van der Kolk et al., 2019).

Subject to very limited evaluation with Developmental Disorder populations (Morris et al., 2020) N=123 adults with mild – moderate ID in secure care (47%) met criteria for DTD)

Common presentation and functioning in mID, bIF and developmental trauma disorder

|                                 | Mild Intellectual Disability                                                                               | Borderline Functioning                                                                                             | Developmental Trauma                                                                                       |
|---------------------------------|------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------|
| <b>Intellectual Functioning</b> | 2 SD's below average                                                                                       | 70-89                                                                                                              | ↓ 8 –10 FSIQ                                                                                               |
| <b>Functional Abilities</b>     | 2 SD Below average                                                                                         | Below average                                                                                                      | Impaired                                                                                                   |
| <b>Emotional Regulation</b>     | Alexithymia<br>Emotional dysregulation*                                                                    | Alexithymia<br>Emotional dysregulation*                                                                            | Alexithymia<br>Emotional dysregulation,<br>impaired self-protection and<br>self-soothing behaviours        |
| <b>Interpersonal skills</b>     | Attachment, TOM                                                                                            | Attachment,                                                                                                        | Significant difficulties in<br>attachment, TOM, maintaining<br>relationships                               |
| <b>Educational attainment</b>   | Deficits in generalising<br>learning outcomes<br>Lower education attainment<br>Increased risk of expulsion | Fewer qualifications (academic<br>and vocational)<br><br>Lower education attainment<br>Increased risk of expulsion | Deficits in generalising learning<br>outcomes<br>Lower education attainment<br>Increased risk of expulsion |
| <b>Life expectancy</b>          | reduced                                                                                                    | Reduced                                                                                                            | reduced                                                                                                    |

# Key Question

Should we delay diagnosing intellectual disabilities in populations exposed to trauma until *after* trauma needs have been addressed?

# Developmental Trauma lens: Assessment implications and opportunities!



- **Overarching:** Widening the hypotheses and assumptions we make about the factors that underpin needs

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- **At the point of referral to a service**
- **Screening for exposure to adversity for all referrals**
  - e.g. ACEs questionnaire (or more detailed alternatives)
  - Pay particular attention to onset and their relationship with developmental milestones
  - Include assessments 'institutional ACEs' and community ACEs
  - Screening for sexual behaviour & self-concept (Denton et al., 2017)
  - Resilience and functional skills measures (Denton et al., 2017)
  - Internal and externalizing behaviours
  - Dissociation?
  - Brief assessment checklist (Goemans et al., 2018)
  - Implications for assessing needs of wider family members & Safeguarding implications?
  - Health related needs (multiple, especially BMI)

# Developmental Trauma lens: Assessment implications



- **Screening for the impact of trauma exposure (current presentation and needs)**

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- Mental Health and wellbeing (inc attachment) and physical health needs
- Monitoring and tracking development (developmental, functional & adaptive behaviours) of those placed outside of the home (Goemans et al., 2018)

- **Adopting a different approach to IQ / cognitive functioning assessment**

- Should IQ tests outcome measure to assess the impact of interventions
- (wish list) fMRI

- **Biological assessments**

- ??Cortisol awakening?? - challenging in not research settings..

- **Risk assessments (harm to others)**

- Some risk assessments have higher number of questions that focus on early experiences of trauma
- Our own study suggests that this can lead to false positives in estimates of risk and inflate risk in institutional settings (in preparation for submission)



# Adopting a Developmental Trauma lens: Treatment implications

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This approach could lead to a reformulation of pathways of care, treatment needs and goals

Is adopting a TIC within ID services sufficient? vs developmental trauma pathways

Children: Intensive (holistic) programmes, similar to the BEIP programme; Number of potential promising programmes including the KINGS-ID programme (whole family approach)

Adults: holistic approach to trauma, not just mental health, but physical health needs need to have parity of esteem to address QoL and life expectancy issues. (SR; Byrne, 2020)

?? Increased emphasis and expectations on education and employment outcomes??

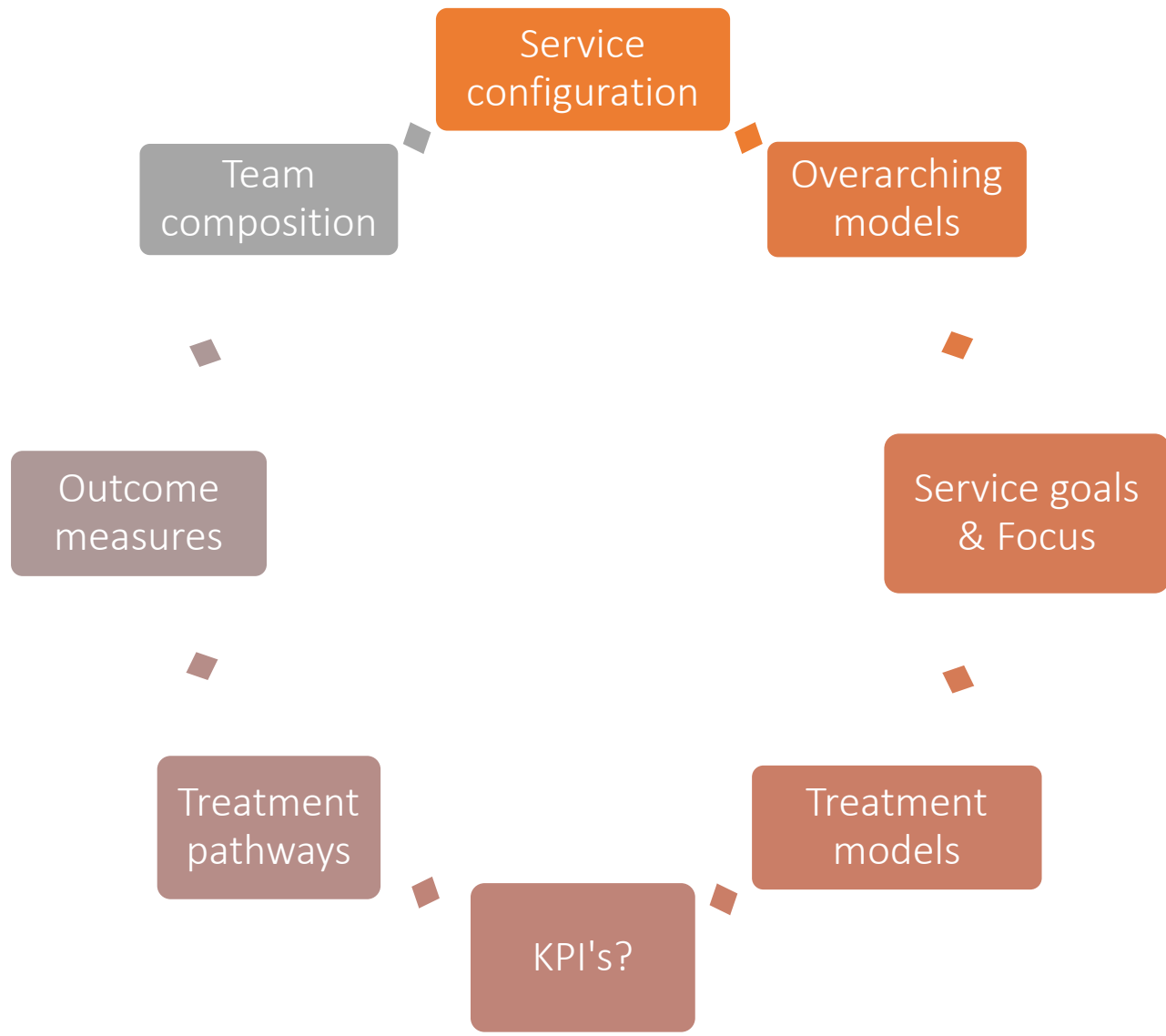
Where should people with dual needs treated?

Yo-yo effect of this population within services between CMHT and Learning Disability Services





# Adopting a Developmental Trauma lens: Service provision implications... or opportunities?



# Costs and benefits of reformulating lower levels of functioning through a trauma lens

- **Costs**

- Could lead to more people falling between services
- Lack of service models and services to meet the need
- False positive results due to overlap with developmental disorders
- ?Impact on alliances with families?
- Impact on the service user's relationship with their families
- Encourage a 'blame' culture.. A new stigma?

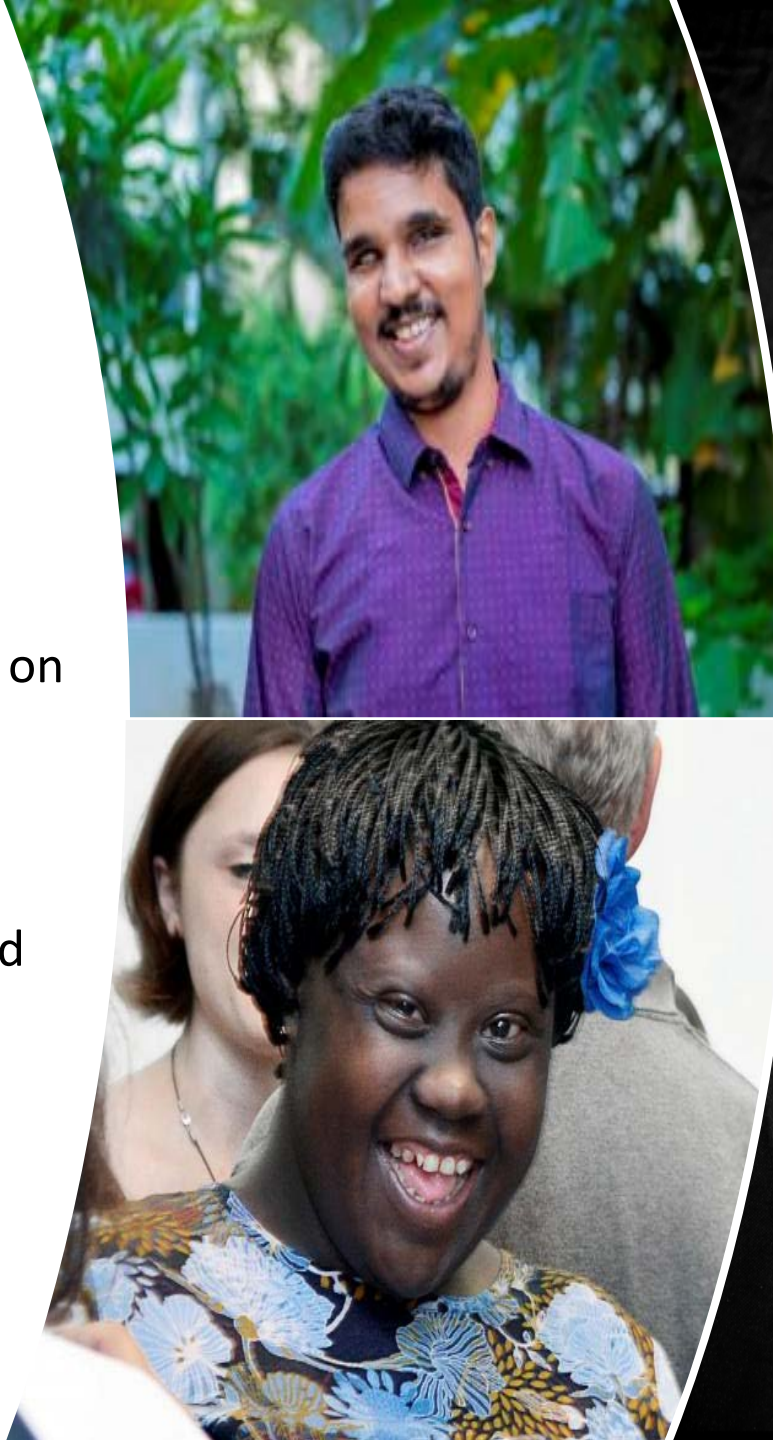
- **Benefits**

- More accurate / valid given differential pathogenesis, biopathology and course
- Developmental Trauma services and pathways?
- More validating to those who have experienced adversity
- More appropriate treatment models
- Widen expectations and goals of outcomes?
- ??better outcomes??
- Better acknowledgement of wider physical health needs

# Next steps: Research Programme

## Systematic programme of study is needed

- Exploration of 'unknown' causes of ID and their relationship with early adversity
- Systematic detection, recording and monitoring of the impact of early adversity on a range of 'life' outcomes
- Exploration of 'institutional' ACEs and developing ID appropriate measures
- Exploration of the impact of trauma focused interventions on functioning, including cognitive functioning.
- Physical health needs



# Summary

People with intellectual disabilities are over represented in all categories of childhood trauma

The relative contribution of trauma to presenting cognitive deficits and functional skills in those with ID diagnoses warrants further exploration

A small subsection of these (mild and borderline functioning) may present with a different pathogenesis, pathobiology and course that differentiates them from other people with intellectual disabilities

Important to have discussions and exploration whether the ID diagnosis is therefore the most appropriate nosology for this population

Different pathways to cognitive and functional deficits may require different approaches to treatment and treatment pathways