

IMAGINE-ID Longitudinal Study: Mental health and behavioural trajectories in children with Autism and an Intellectual Disability of genetic aetiology

Wolstencroft J., Srinivasan R., IMAGINE ID Consortium & Skuse D.

UCL Great Ormond Street Institute of Child Health



BACKGROUND

Intellectual and developmental disability (IDD) is characterised by significant limitations in cognitive functioning and adaptive behaviour and is often associated with behavioural and mental health problems at all life stages.

IMAGINE-2 is a national longitudinal study of behavioural problems and psychiatric risk in children with IDD of known genetic origin. Autism is the most common co-occurring condition in the cohort.

OBJECTIVE: Examine the trajectory of development of mental health and behavioural difficulties experienced by participants with IDD and autism in childhood.

METHODS

IMAGINE participants (4-22 years) were initially recruited from UK NHS Genetic Services between 2015-2020.

Caregivers completed the Strengths and Difficulties Questionnaire (SDQ) in 2015-20 (T1) and again in 2021 (T2).

Strengths and Difficulties Questionnaire (SDQ)

- Assesses children's emotional and behavioural adjustment in dimensional terms on subscales relating to emotional difficulties, conduct problems, hyperactivity and prosocial behaviour.

- Validated for children with IDD.

RESULTS

- SDQ data was obtained at both timepoints on 1,064 participants children aged 4 to 22 (M=9.3, SD=4.2). Of these, 41.4% (n=441) reported their child had been diagnosed with autism.

- At T1 and T2 the mean total SDQ score for participants with autism was in the 'very high' severity range (M T1 =21.9, SD T1=5.8; M T2=20.5, SD T2=5.9).

- At T1 64% of participants with autism had scores in the very high range, 18% in the high range, 10% above average range and 8% in the average range (Figure 1).

- 59% of participants remained in the same severity band category from T1 to T2, 17.4% deteriorated and moved into a higher severity band, whereas 20.8% improved and moved to a lower severity band.

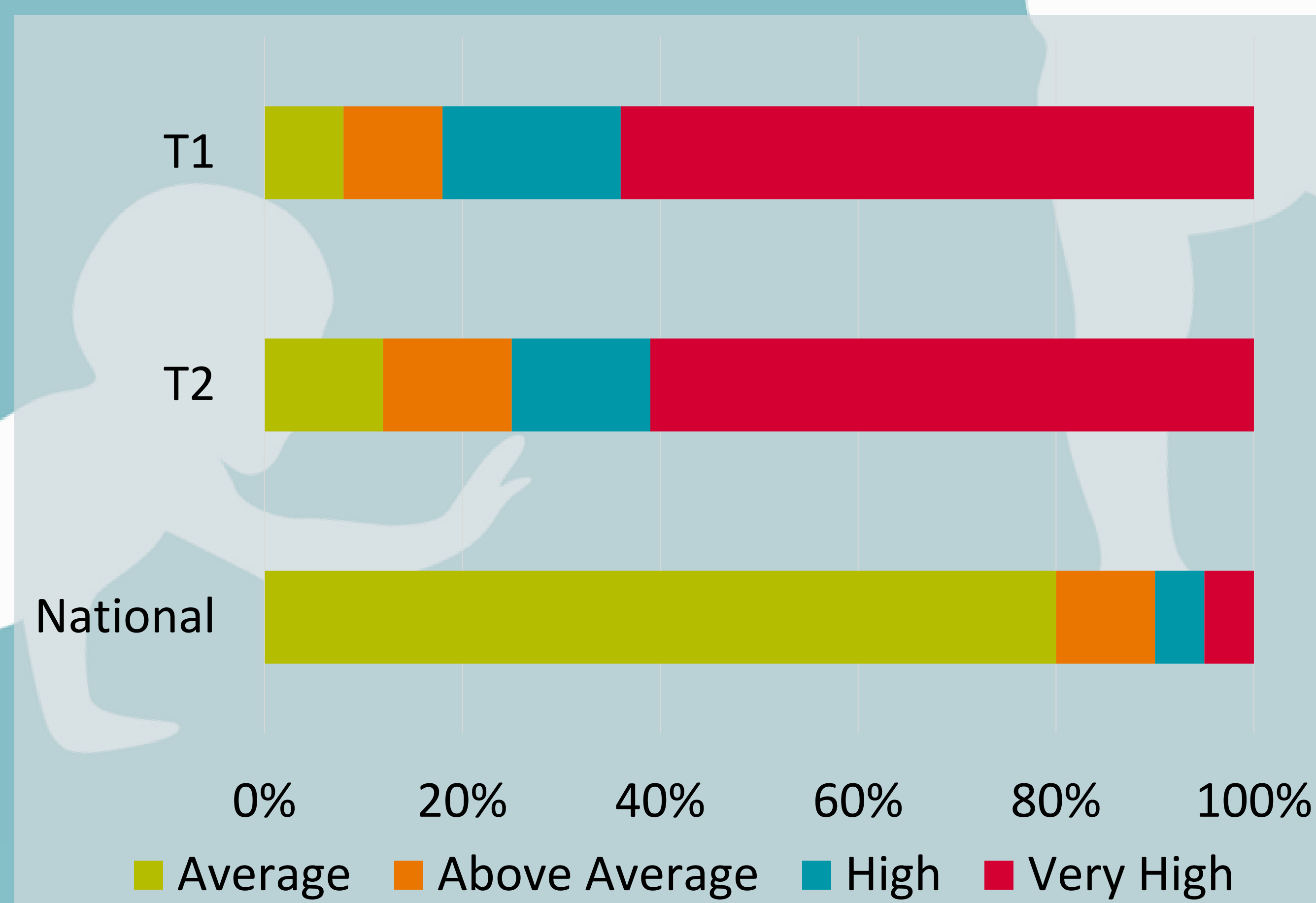


Figure 1. SDQ severity band changes over time

- Paired comparison of the SDQ subscale scores show a significant reduction in conduct and hyperactivity symptoms and a significant improvement in prosocial ability from T1 to T2. Emotional difficulties remained in the high severity range from T1 to T2 (Figure 2).

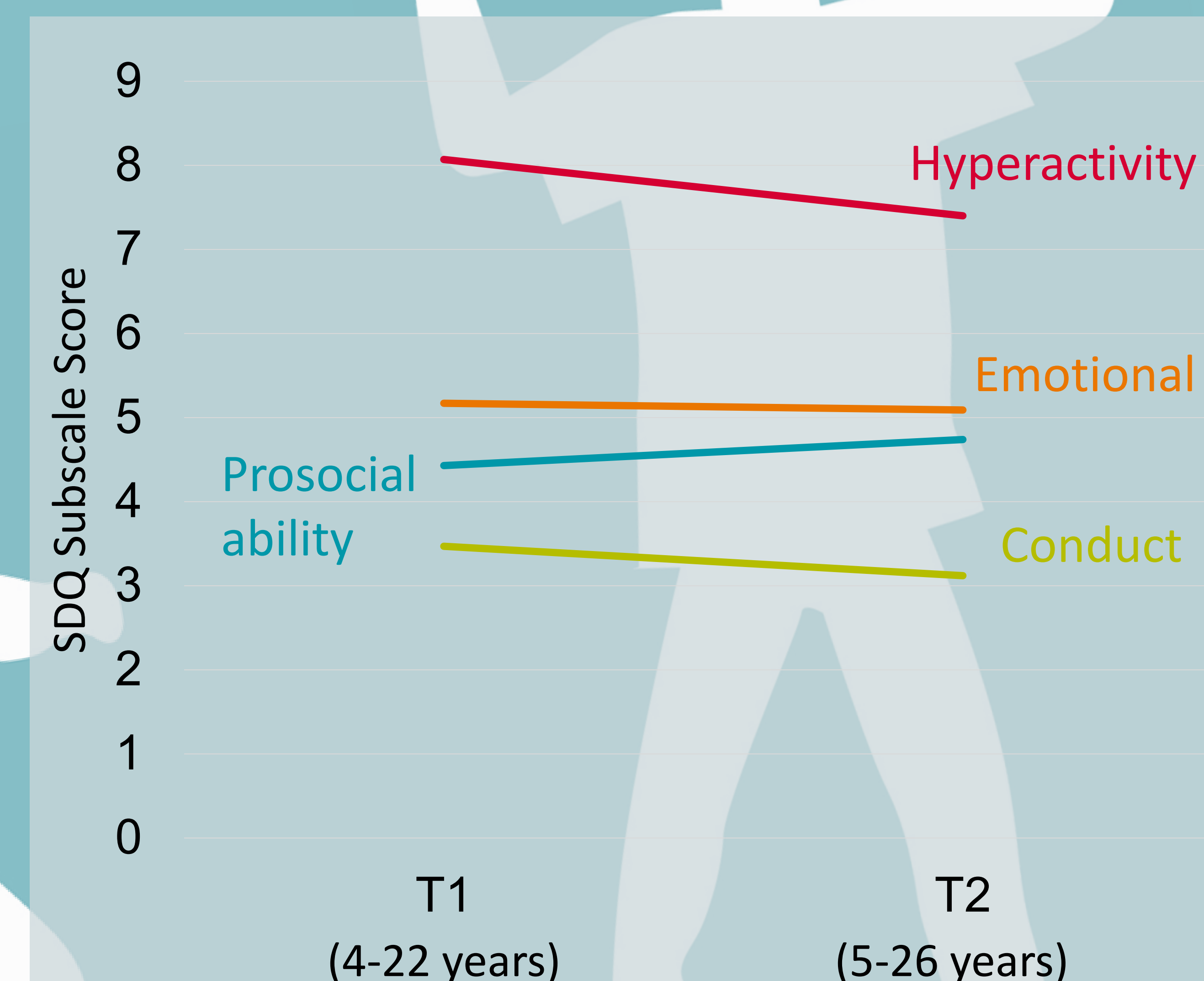


Figure 2. SDQ subscale score changes over time

INTERPRETATION

- In those with co-occurring IDD and autism there are reductions in conduct and hyperactivity difficulties and improvements in prosocial behaviour in childhood. However, emotional difficulties remained.

- Only 1 in 5 participants with autism experienced clinically significant improvements on their overall emotional and behavioural adjustment during childhood. Emotional difficulties appear not to resolve developmentally and may require targeted intervention.