OPINION

Are we missing obsessive–compulsive disorder in children with severe intellectual disability?

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BJPsych Bulletin (2026) Page 1 of 4, doi:10.1192/bjb.2026.10285

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First received 22 Apr 2026 UTC, final revision 17 Jun 2026 UTC, accepted 12 Aug 2026 UTC

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Summary Obsessive–compulsive disorder (OCD) is being missed in children with severe intellectual disability. Their compulsive behaviours are routinely attributed to autism spectrum disorder or dismissed as challenging behaviour, without systematic consideration of OCD. I argue that this misattribution is predictable, consequential and correctable. The key diagnostic tool is the ego-dystonic/ego-syntonic distinction: OCD rituals are distressing to the child and a change from their baseline, whereas autistic repetitive behaviours are typically comforting. When this distinction is applied, and OCD is treated with modified exposure and response prevention and selective serotonin reuptake inhibitors, outcomes can be transformative. A dedicated evidence base for this population is urgently needed.

Keywords Obsessive–compulsive disorder; child and adolescent psychiatry; intellectual disability; attention-deficit hyperactivity disorder; autism spectrum disorders.

I want to argue that we are missing obsessive–compulsive disorder (OCD) in children with severe intellectual disability and that the consequences are serious. OCD is defined by intrusive, unwanted thoughts (obsessions) and the repetitive behaviours performed to neutralise the distress they cause (compulsions). OCD affects an estimated 1–2% of young people, at least 130 000 children in the UK at any 1 time, and already carries the longest duration of untreated illness of almost any psychiatric disorder.[1,2] Children with intellectual disability carry a substantially elevated overall burden of psychiatric disorder,[3] yet OCD rarely features in clinical formulations for this group. In children with severe intellectual disability specifically, who cannot reliably report their inner experience and whose diagnostic picture is complicated by a very high background rate of repetitive behaviours due to co-occurring autism, I believe the rate of missed and delayed OCD diagnosis is considerably worse than in the general population and that existing epidemiological estimates are likely to undercount it, since the instruments on which they depend have generally not been adapted for non-verbal populations. A Swedish national registry study supports this concern: OCD prevalence in people with intellectual disability was paradoxically lower in those with severe/profound intellectual disability than in those with mild or moderate intellectual disability, a pattern the authors attribute partly to greater diagnostic difficulty rather than genuinely lower rates.[4]

The usual explanation for this gap is clinical difficulty: these children are hard to assess, the literature is sparse and validated instruments do not exist. All of that is true. But I think there is a more fundamental problem: in my clinical experience, an unspoken assumption persists that children who cannot report obsessional thoughts cannot have OCD. This reflects a broader pattern of diagnostic overshadowing in this population, where symptoms of a treatable co-occurring condition are attributed instead to the child's underlying disability.[5] This assumption is wrong. The cognitive capacity required to experience ego-dystonic, anxiety-driven compulsions is not contingent on the ability to articulate them. There is no diagnostic requirement that obsessions be verbally reported. This matters because the case vignettes that follow show OCD presenting as severe, escalating distress and family disruption that was initially misread as autism, attention-deficit hyperactivity disorder (ADHD) side-effects or simple defiance; in each, recognising it changed the outcome. This paper sets out why this diagnosis is missed, offers the ego-dystonic/ego-syntonic distinction as a practical tool for identifying it without verbal report, and uses three cases vignettes to show that recognising and treating it can transform outcomes.

The diagnostic pivot: ego-dystonic versus ego-syntonic

The most important clinical question when evaluating repetitive behaviour in a child with severe intellectual disability is not what the behaviour looks like but what it does for the child. Is it something they want to do, or something

https://doi.org/10.1192/bjb.2026.10285 Published online by Cambridge University Press

they feel compelled to do against their own wishes? Behaviours are ego-syntonic when experienced as harmonious with a person's own wishes, and ego-dystonic when experienced as unwanted or imposed against their will. This distinction, developed to separate the comfortable repetitive behaviours of autism from the distressing compulsions of OCD, underpins the argument that follows.

Autistic repetitive behaviours are ego-syntonic. They are comforting, regulating or pleasurable. They reduce distress; they are not the source of it. A behaviour that helps a child manage their internal state is not OCD, regardless of how exhausting or disruptive it is for the adults around them.[6,7] This is a clinically useful generalisation rather than an absolute rule: a systematic review found considerable overlap between autism and OCD in repetitive behaviour at a group level, and noted that the ego-dystonic/ego-syntonic distinction has rarely been studied in people with intellectual impairment, where it must be inferred behaviourally rather than reported.[7]

OCD compulsions are ego-dystonic. The child is driven to perform them, by anxiety or an unbearable sense that something is wrong or incomplete, but derives no lasting comfort. The ritual must be performed, and performed correctly, but it does not help, because as soon as one ritual is completed, the next begins. Interruption causes severe distress, and often the child feels the need to restart from the beginning – not because the activity was enjoyable and has been disrupted, but because the sequence has not been completed to the point of relief.[6,8]

A second signal is temporal: OCD, unlike autism, ADHD or intellectual disability itself, is not present from birth. A history of onset, these specific behaviours beginning in recent months or years in a child who did not previously show them, is a powerful diagnostic indicator. When a family reports that their child has changed, that something new and relentless has taken hold, OCD must be in the differential.

I should be clear that the ego-dystonic/ego-syntonic distinction is a clinical rule of thumb, not a clear dividing line. In children with severe intellectual disability and significant comorbid anxiety, the picture may be genuinely ambiguous, and the distinction can be hard to operationalise reliably in children who are non-verbal. It is a starting point for structured clinical thinking, not a substitute for thorough multidisciplinary assessment. In practice, ego-dystonicity can often be inferred behaviourally rather than verbally: facial affect during and after rituals (distress rather than calm), the presence of restart behaviour when a sequence is interrupted, and caregiver report of a child who appears compelled rather than absorbed are all useful proxies.

Three case vignettes

The following case vignettes, which are composites of real cases from my clinical practice, with details changed to preserve confidentiality, illustrate how this distinction operates.

Case 1: The 'controlling' child

A 10-year-old girl with severe intellectual disability developed a progressive need to control the positions of family members throughout the home: her father at his desk, her mother in the kitchen, her brother at his computer. These behaviours had escalated progressively over a few months, in a child who had not previously shown them. She also checked repeatedly that objects were in their correct places according to her wishes, for example she insisted that all cushions in the living room were heaped in the corner of the room. When family members moved, or when anything in the house was moved out of place, she became markedly distressed and physically tried to put people and objects back to where she felt they belonged. None of this had been present earlier in childhood. She was not comforted by completing the rituals; she was driven to walk around checking that all was in order the whole time, with distress mounting if interrupted or when her wishes were thwarted. Sertraline was prescribed. Initial response was poor, and on review the dispensed liquid preparation proved to be half the intended concentration, a well-recognised pharmacological pitfall in this population. Once corrected and titrated to 200 mg per day, her OCD resolved substantially and family life normalised.

Case 2: The child who 'got worse on ADHD medication'

A 12-year-old boy with severe intellectual disability and ADHD was referred for antipsychotic medication, having apparently deteriorated on every stimulant and non-stimulant trialled. His parents stated that he was angrier and more anxious on ADHD medication. On further questioning, it emerged that he engaged in extensive checking rituals, verifying windows, sockets and switches, and became distressed and angry when family members did not comply with his rules. Careful history revealed that these checking behaviours had in fact begun over a year before the referral, pre-dating ADHD treatment. Before ADHD treatment, his limited attentional capacity had made the rituals easier for carers to interrupt. Since medicated for ADHD, his improved concentration had enabled him to pursue his compulsions more effectively. The ego-dystonic quality was clear from collateral history: he derived no pleasure and was distressed until each sequence was complete. OCD was treated with high-dose sertraline before ADHD medications were restarted. He responded well and did not require antipsychotic medication.

Case 3: The young man who 'was addicted to stimming'

A 16-year-old boy with severe intellectual disability was brought by his mother, who believed he was 'addicted to stimming'. Turning off the tap after brushing his teeth required 15–20 min of on–off cycling before it felt 'just right'. It took him 2 h to get from his bedroom to the front door, as he would walk in a certain way and then return to the starting point to redo it over and over again. She also described a 3 h bedtime routine, with each step needing to be completed to his satisfaction before he could proceed. If interrupted, he restarted from the beginning. On one evening he fell asleep mid-routine attempting to straighten his bedsheets. On waking the next morning, he was distressed to find the sequence incomplete and he immediately resumed it and tried to get into bed to go to sleep! This observed sequence, distress on waking to an incomplete ritual, followed by

https://doi.org/10.1192/bjb.2026.10285 Published online by Cambridge University Press

immediate resumption before returning to sleep, is itself behavioural evidence of ego-dystonicity independent of his mother's account. His mother was surprised to learn that stimming is typically experienced as pleasurable. She acknowledged that her son found his routines entirely joyless, obligatory and that he was visibly relieved only when each stage was done. This reframing, from ego-syntonic stimming to ego-dystonic compulsion, was the diagnostic pivot. He responded well to sertraline.

When OCD is identified: treatment principles

Identifying OCD is only useful if it changes management; the following principles, illustrated by the cases above, set out how treatment differs once the diagnosis is made. The National Institute for Health and Care Excellence guideline (NICE CG31) recommends a stepped-care approach, beginning with cognitive–behavioural therapy incorporating exposure and response prevention (ERP), with selective serotonin reuptake inhibitor pharmacotherapy added for children with moderate to severe impairment who have not responded adequately to psychological treatment alone.[1] Sertraline is the first-line choice: it is licensed in the UK for OCD in children and young people aged 6–17, with an evidence base from randomised controlled trials in this age group. Therapeutic doses for OCD, up to 200 mg per day, are substantially higher than those used for depression or anxiety, and underdosing is a common reason for apparent treatment failure. Liquid preparations require particular vigilance as there are different strengths that can be used.

No equivalent evidence base exists for children with severe intellectual disability. The treatment recommendations that follow are extrapolated from the general OCD literature and from my own clinical experience; they are not derived from evidence in children with severe intellectual disability, and should be understood as such. With that caveat, the NICE stepped-care framework remains the most appropriate starting point, with the following adaptations. ERP requires modification – framing OCD as something external, something making the child act rather than a reflection of their character, reduces distress and helps carers respond to the OCD rather than to the child. All involved adults must work consistently to support resistance to rituals rather than accommodating them. Family accommodation is one of the strongest predictors of poor outcome in OCD,[9] and the clinical rationale for addressing it is compelling even in the absence of specific evidence in the intellectual disability population. Parents often need substantial support to tolerate their child's distress when rituals are interrupted, particularly if they have problems with anxiety themselves, and this work may need to precede consistent implementation of response prevention.

Where ADHD co-occurs, addressing the OCD first is generally advisable: ADHD medication can intensify OCD symptomatology, and as Case 2 illustrates, what looks like ADHD medication failure may be unmasked OCD.[6] OCD and ADHD co-occur at rates substantially above chance, and the combination presents particular diagnostic and management challenges.[10] This sequencing recommendation is based on clinical reasoning and case experience rather than controlled evidence, and individual circumstances will sometimes warrant a different approach. In this population, non-stimulant approaches to ADHD may also be preferable once OCD is stabilised, as stimulants are both less effective and less well-tolerated in children with intellectual disability. Clonidine in particular has shown evidence of benefit for ADHD, sleep difficulties and behaviours that challenge in children with intellectual disability, and is generally well tolerated in this group.[11]

What needs to change

OCD in children with severe intellectual disability is being subsumed into autism formulations or non-specific challenging behaviour frameworks without the differential ever being properly considered. This pattern has been demonstrated empirically in verbal autistic youth: clinician-observed repetitive behaviour was better explained by children's own reports of OCD-like distress than by parent reports, suggesting that observers default to attributing distressing repetitive behaviour to autism, a risk that can only be greater where the child cannot self-report at all.[12] The consequences are considerable: untreated OCD disrupts development, devastates family functioning and compounds an already significant disability burden. A longer duration of untreated OCD is associated with poorer treatment response and, from neuroimaging data, progressive structural changes in OCD-relevant brain circuits.[2,13] Children with severe intellectual disability, whose developmental trajectory is already constrained, are especially vulnerable to these cumulative effects.

What is needed, immediately and practically, is for OCD to be placed explicitly in the differential diagnosis whenever a child with severe intellectual disability presents with new or escalating repetitive behaviours. Two questions provide a useful clinical starting point: Does the behaviour distress the child? Does it represent a change from their earlier baseline? An affirmative answer to either warrants proper multidisciplinary assessment, with structured observation across home and school settings and collateral history focused on the ego-dystonic/ego-syntonic distinction. This is consistent with case-level experience elsewhere in intellectual disability psychiatry, where reliance on directly observable behaviour, rather than inferred inner distress, has been recommended as the most reliable basis for diagnosing OCD in this population.[8]

In short: this diagnosis is missed, it can be identified without verbal report using the distinction set out above and treating it transforms outcomes. Longer term, this population urgently needs its own evidence base: epidemiological studies using adapted non-verbal methods, empirical testing of the diagnostic criteria as applied behaviourally, and treatment trials for both pharmacological and psychological interventions. We do not yet know how many children with severe intellectual disability have OCD. What my clinical experience tells me is that it is more than we think, and that when we find it and treat it, the results can be transformative.

About the author

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https://doi.org/10.1192/bjb.2026.10285 Published online by Cambridge University Press

Acknowledgement

Artificial Intelligence use: No artificial intelligence tools have been used in the research or writing process for this manuscript.

Funding

This work received no specific grant from any funding agency, commercial or not-for-profit sectors.

Declaration of interest

None.

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