

# Childhood risk factors and clinical and service outcomes in adulthood in people with intellectual disabilities

B. Perera, S. Mufti, C. Norris-Grey, A. Baksh, V. Totsika, A. Hassiotis, P. Hurks and T. van Amelsvoort

## Background

Adults with intellectual disability experience increased rates of mental health disorders and adverse mental health outcomes.

## Aim

Explore childhood risk factors associated with adverse mental health outcomes during adulthood as defined by high cost of care, use of psychotropic medication without a severe mental illness and psychiatric hospital admissions.

## Method

Data on 137 adults with intellectual disability were collected through an intellectual disability community service in an inner London borough. Childhood modifiable and non-modifiable risk factors were extracted from records to map onto variables identified as potential risk factors. Logistic and linear regression models were employed to analyse their associations with adverse outcomes.

## Results

We showed that the co-occurrence of intellectual disability with autism spectrum disorder and/or attention-deficit hyperactivity disorder (ADHD) were associated with psychotropic medication use and high-cost care packages. However, when challenging behaviour during childhood was added, ADHD and autism spectrum disorder were no longer significant and challenging

behaviour better explained medication prescribing and higher cost care. In addition, the severity of intellectual disability was associated with higher cost care packages. Ethnicity (Black and mixed) also predicted higher cost of care.

## Conclusions

Challenging behaviour during childhood emerged as a critical variable affecting outcomes in young adulthood and mediated the association between adult adverse mental health outcomes and co-occurring neurodevelopmental conditions, that is, ADHD and autism. These findings emphasise the need for effective early intervention strategies to address challenging behaviour during childhood. Such interventions for challenging behaviour will need to take into consideration autism and ADHD.

## Keywords

Intellectual disability; risk factors; challenging behaviour; attention-deficit hyperactivity disorder; mental health outcomes.

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Intellectual disability is characterised by significant impairments in cognitive, social, functional and adaptive skills, including activities of daily living, with onset during the developmental period.<sup>1,2</sup> Estimates suggest that approximately 1.5–2% of the population has intellectual disability.<sup>3</sup> People with intellectual disability experience high rates of co-occurring mental health disorders and challenging behaviour compared to those without intellectual disability.<sup>4</sup> Studies indicate that people with intellectual disability are three to four times more likely to have at least one other mental health disorder, such as mood disorders, anxiety disorders, schizophrenia and personality disorders, compared to individuals without intellectual disability.<sup>5–8</sup> Challenging behaviours, that is, behaviours that place an individual or those in his environment at risk of harm or exclusion,<sup>9</sup> are frequently observed among individuals with intellectual disability, prompting mental health services to provide assessments and interventions. It is estimated that about one in five people with intellectual disability known to mental health services present with challenging behaviour.<sup>10</sup> Therefore, gaining a better understanding of the presentation and factors contributing to the increased risk of mental disorders and challenging behaviour in adults with intellectual disability is important to tackle this disparity in mental health among people with intellectual disability.<sup>11,12</sup>

## Risk factors

Studies focusing on the adult population without intellectual disability show multiple factors that increase the risk of mental

illnesses. These include biological, psychological and social factors, such as genetics, gender, a history of previous mental illness, medical illnesses, substance misuse and childhood adversities.<sup>13</sup> Studies in non-intellectual disability populations have demonstrated significant functional impairments, including mental illnesses among people with neurodevelopmental disorders such as attention-deficit hyperactivity disorder (ADHD).<sup>14</sup> Individuals with intellectual disability face comparable risk factors associated with mental disorders and challenging behaviour.<sup>15</sup> Communication impairments, lack of support systems, severity of intellectual disability and residing in institutional or congregate care settings are some factors specifically related to people with intellectual disability that contribute to increased mental health disorders.<sup>16,17</sup>

Studies have reported similar risk factors that increase the likelihood of challenging behaviour in intellectual disability. Factors such as the presence of a mental disorder, younger age, psychotropic medication use, pervasive developmental disorders, mood instability, agitation, irritability, increased contact with mental health professionals, underlying genetic disorders and sensory deficits are highly prevalent among people with intellectual disability experiencing challenging behaviour.<sup>10</sup>

## Clinical outcomes

Research indicates that individuals with intellectual disability often experience prolonged stays in psychiatric hospitals compared to those without intellectual disability.<sup>18</sup> It is estimated that people with intellectual disability have 1.5 times longer hospital stays

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compared to people without.<sup>19</sup> In addition, support required for individuals with intellectual disability with mental health or behavioural challenges demands increased resources, leading to significantly higher care costs in the community compared to those without intellectual disability.<sup>20</sup> The presence of a mental disorder further increases the support needs and poses more demands on the care system.<sup>21</sup> Studies have shown that people with intellectual disability are more likely to take psychotropic medications, including antipsychotic medications, even in the absence of severe mental illness.<sup>22</sup> Hospital admissions, use of psychotropic medications in the absence of mental illness and higher cost of care could also be considered as important indicators of adverse mental health outcomes against the current service backdrop of limited availability of in-patient beds for people with intellectual disability, the financial costs of services supporting people with intellectual disability and the ongoing efforts to minimise the use of psychotropic medications.<sup>23,24</sup>

Studies in the general population have shown that up to three-quarters of mental disorders occur before age 25 years, emphasising the crucial need to address mental health concerns during this period.<sup>25</sup> Similar findings have been reported in studies in people with intellectual disability suggesting that owing to reasons such as increased challenges when transitioning into adulthood, young adults (age 18–24 years) with intellectual disability often require access to intellectual disability mental health services.<sup>26</sup> Therefore, focusing on the age group of 18–24 can be argued as important to be able to understand factors associated with clinical and service outcomes in young adults.

Aim

Understanding risk factors for adverse mental health outcomes and their significance to clinical practice can prompt service improvements through preventive interventions that could drive changes at the service level, ultimately enhancing outcomes for individuals with intellectual disability. Considering the above, our study aimed to examine the association between childhood risk factors and adverse mental health outcomes in young adults with intellectual disability.

Method

Data were drawn from electronic records of adults with intellectual disability aged 18–24 years registered with an intellectual disability service for adults in an inner London borough with a population of 280 000. There were approximately 700 adults with intellectual disability registered with the service. Two psychiatrists on the team reviewed the existing electronic clinical data. They retrospectively extracted information related to childhood risk factors and three adverse clinical and service outcomes (Table 1) to complete the data collecting proforma. Risk factors were chosen for their clinical relevance, their potential association with an increased risk of adverse mental health outcomes and availability to collect by clinicians as part of a service evaluation. Modifiable and non-modifiable risk factors were considered. Non-modifiable variables encompassed the level of intellectual disability, ethnicity and co-occurring diagnoses of autism and ADHD. Modifiable risk factors included challenging behaviour, psychiatric hospital admissions, mental illness, Child and Adolescent Mental Health Service (CAMHS) involvement during childhood (below 18), being a looked after child and the place of residence by the age of 16 years. Diagnoses of intellectual disability, autism, ADHD and mental illness were often made by clinicians from clinical history rather than using validated tools. Neurodevelopmental disorder diagnoses were based on DSM-5.<sup>1</sup> Diagnoses of mental illnesses were made using ICD-10.<sup>27</sup> Challenging behaviour was included if it was described as challenging behaviour or in similar terms in clinical records.

Table 1 Data collected

| Adverse mental health outcome: (between age 18 and 24)                                              | Childhood risk factors (before age of 18)                                                |
|-----------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------|
| 1. Use of psychotropic medication in the absence of severe mental illness <sup>a</sup> in adulthood | 1. Level of intellectual disability                                                      |
| 2. Cost of care packages in adulthood                                                               | 2. Ethnicity                                                                             |
| 3. In-patient psychiatric admission during adulthood                                                | 3. Diagnosis of autism                                                                   |
|                                                                                                     | 4. Diagnosis of ADHD                                                                     |
|                                                                                                     | 5. Challenging behaviour before the age of 18 years                                      |
|                                                                                                     | 6. Psychiatric hospital admission before the age of 18 years                             |
|                                                                                                     | 7. Presence of mental illness before the age of 18 years                                 |
|                                                                                                     | 8. Involvement of Child and Adolescence Mental Health Services (CAMHSs)                  |
|                                                                                                     | 9. Looked after child status before the age of 16 years                                  |
|                                                                                                     | 10. Place of residence (care setting or family home) at the age of 16 years <sup>b</sup> |

ADHD, attention-deficit hyperactivity disorder.  
a. Severe mental illness – bipolar affective disorder (F31 ICD-10) and/or any psychotic disorder (F20-29 ICD-10)  
b. Place of residence at the age of 16 years was used to indicate where the person lived the longest between the ages of 0 and 16 years.

Ethics

This study constituted a service evaluation of the clinical care of the service. The National Health Service (NHS) Health Research Authority tool (<http://www.hra-decisiontools.org.uk/research/index.html>) confirmed that no ethical approval was required for this project. All information gathering complied with the UK Data Protection Act (2018) requirements. To ensure confidentiality, data were anonymised before analysis and handled on a service computer by authorised individuals to access the data.

Statistical analysis

Logistic and linear regression models were employed to examine factors associated with psychotropic medication use in the absence of severe mental illness during childhood. Odds ratios with 95% confidence intervals (95% CI) are reported. Model 1 incorporated non-modifiable risk factors (level of intellectual disability, ethnicity and presence of other co-occurring neurodevelopmental disorders) as covariates. In Model 2, childhood modifiable variables (challenging behaviour, CAMHS involvement, mental illness during childhood and living setting at age 16 years) were included to examine their impact on psychotropic medication prescription while adjusting for non-modifiable risk factors.

A similar approach was adopted for modelling high-cost care packages in adulthood using multiple linear regression. The outcome variable was log-transformed to account for violation of normality and was then back-transformed for reporting purposes. All analyses were conducted using R software (version 4.3.1 for MacOS, R Core Team, Vienna, Austria; <https://www.R-project.org/>).<sup>28</sup> The reference groups for all analyses were mild intellectual disability for the level of intellectual disability, White for ethnicity and the absence of specific conditions for other categories. We followed the approach suggested by Rothman<sup>29</sup> and did not adjust for multiple comparisons.

Results

Some 137 adults with intellectual disability aged 18–24 years were found in the whole caseload (Table 2). Among them, 27 (20.1%)

**Table 2** Cohort characteristics

| Variables                                                                                |               | N (%)       |
|------------------------------------------------------------------------------------------|---------------|-------------|
| Total number of people with intellectual disability aged 18–24 years                     |               | 137         |
| Level of intellectual disability (missing data on level of intellectual disability – 3)  | Mild          | 27 (20.1%)  |
|                                                                                          | Moderate      | 67 (50.0%)  |
|                                                                                          | Severe        | 31 (23.1%)  |
|                                                                                          | Profound      | 9 (6.7%)    |
| Ethnicity                                                                                | White         | 38 (27.7%)  |
|                                                                                          | Asian         | 9 (6.6%)    |
|                                                                                          | Black         | 62 (45.3%)  |
|                                                                                          | Mixed         | 7 (5.1%)    |
|                                                                                          | Other unknown | 21 (15.3%)  |
| Autism                                                                                   | Yes           | 87 (63.5%)  |
|                                                                                          | No            | 50 (36.5%)  |
| ADHD                                                                                     | Yes           | 26 (19%)    |
|                                                                                          | No            | 111 (81%)   |
| Both ADHD and autism                                                                     | Yes           | 23 (17%)    |
|                                                                                          | No            | 114 (83%)   |
| Challenging behaviour before the age of 18 years (missing data – 2)                      | Yes           | 72 (53.3%)  |
|                                                                                          | No            | 63 (46.7%)  |
| Involvement of Children and Adolescent Mental Health Services before the age of 18 years | Yes           | 66 (48.2%)  |
|                                                                                          | No            | 71 (51.8%)  |
| Diagnosis of any mental illness before the age of 18 years (missing data – 1)            | Yes           | 23 (16.9%)  |
|                                                                                          | No            | 113 (83.1%) |
| Living setting at the age of 16 years (missing data – 1)                                 | Family        | 127 (93.4%) |
|                                                                                          | Care          | 9 (6.6%)    |
| Categorised as a 'looked after child' before the age of 16 years                         | Yes           | 12 (8.8%)   |
|                                                                                          | No            | 125 (91.2%) |

ADHD, attention-deficit hyperactivity disorder.

had mild intellectual disability while nearly 80% had moderate to profound intellectual disability. The largest ethnic group identified was Black (45.3%) followed by White individuals (27.7%). Around 63% of the adults with intellectual disability also had a diagnosis of autism, 19% had a diagnosis of ADHD and 17% had both ADHD and autism. Some 53.3% were described as presenting with challenging behaviour. Out of those presenting with challenging behaviour, 27% had a diagnosis of ADHD and 80% had autism. Nearly half of the adults with intellectual disability had utilised CAMHSs during their childhood. Some 23 (16.9%) of the adults with intellectual disability received a diagnosis of mental illness before the age of 18 years. The majority (93.4%) lived with their families during childhood, with only a small minority in care settings. In addition, 8.8% of the adults with intellectual disability were classified as a 'looked after child'.

In terms of adverse mental health outcomes (Table 3), 28 adults with intellectual disability (20.6%) were taking psychotropic medications without a diagnosis of severe mental illness. The cost of care packages per annum varied widely, ranging from £1052 to £288 312, with a mean cost of £34 947. There were only four patients needing psychiatric hospital admission between the ages of 18 and 24 years.

**Table 3** Adverse mental health outcomes

|                                                                                    |                             |             |
|------------------------------------------------------------------------------------|-----------------------------|-------------|
| Use of psychotropic medications without a severe mental illness (missing data – 1) | Yes                         | 28 (20.6%)  |
|                                                                                    | No                          | 108 (79.4%) |
| Cost of care package                                                               | Mean – £34 947.28           |             |
|                                                                                    | Range – £1052.44–288 312.40 |             |
| Psychiatric hospital admission between the ages of 18 and 24                       | Yes                         | 4 (2.9%)    |
|                                                                                    | No                          | 133 (97.1%) |

Table 4 presents the odds ratios, 95% CIs and *P*-values for predicting psychotropic medication prescribing without a severe mental illness in adulthood based on childhood risk factors. Model 1 indicated that the severity of intellectual disability and ethnicity did not predict psychotropic medication use. Both autism and ADHD independently predicted the risk of using such psychotropic medications. However, in Model 2, the inclusion of challenging behaviour, CAMHS involvement and mental illness resulted in ADHD and autism no longer being significantly associated with psychotropic medication prescribing. Challenging behaviour during childhood was the best predictor for psychotropic medication prescribing in adulthood (odds ratio 11.86, 95% CI 1.85–235.95, *P* = 0.028).

Table 5 displays the  $\exp(\beta)$ , 95% CIs and *P*-values for childhood risk factors predicting care package costs during adulthood. This analysis showed that autism, ADHD, increasing severity of intellectual disability and specific ethnicities initially predicted high-cost packages. However, when adjusting for challenging behaviour, CAMHS involvement, mental illness during childhood and living in a care setting in Model 2, ADHD and autism diagnoses were not significantly associated with higher cost packages. Nevertheless, intellectual disability severity and Black and mixed ethnicity status were associated with higher cost packages, while adjusting for the modifiable covariates. Furthermore, challenging behaviour emerged as an independent predictor, significantly associated with high-cost care packages compared to those who did not have challenging behaviour ( $\exp(\beta)$  = 1.79, 95% CI 1.19–2.70, *P* = 0.006). Living in a care setting at the age of 16 years also showed an association with higher cost packages ( $\exp(\beta)$  = –4.93, 95% CI 1.83–13.28, *P* = 0.002). Childhood mental illness and CAMHS involvement were not statistically significantly associated with high-cost care packages compared to no childhood mental illness or CAMHS involvement.

## Discussion

Even though studies have highlighted various childhood factors affecting mental health outcomes in people with intellectual disability, there is a lack of evidence on factors associated with mental health-related adverse outcomes, such as hospital admissions, psychotropic medication prescribing in the absence of severe mental illness and higher cost care packages. The present study focused on these three important clinical outcomes that are directly relevant to patients, carers, clinicians, commissioners and the wider public because of their implications for the person with intellectual disability and the care system. Out of the three outcomes, psychiatric inpatient admissions were infrequent in the group we considered and, because of this, were not included in the models.

This study demonstrated that the presence of autism and ADHD (when challenging behaviour was not adjusted for in the models) were associated with higher cost packages and the use of psychotropic medications without a severe mental illness during adulthood. To compare, studies within a non-intellectual disability context consistently show that ADHD is associated with significant functional impairments,<sup>30,31</sup> persisting even after a 33-year follow-up.<sup>32</sup> However, the evidence on functional impairment and long-term outcomes of ADHD in people with intellectual disability remains underexplored. Challenging behaviour has been suggested as the main functional impairment among people with ADHD and intellectual disability, with nearly 70% of adults with ADHD and intellectual disability presenting with behavioural challenges.<sup>33</sup> Therefore, it can be hypothesised that challenging behaviour among people with ADHD and intellectual disability might explain the prescribing of psychotropic medications without a

**Table 4** Association between risk factors and use of psychotropic medications without a severe mental illness

|                                     | Model 1    |            |         | Model 2    |             |         |
|-------------------------------------|------------|------------|---------|------------|-------------|---------|
|                                     | Odds ratio | 95% CI     | P-value | Odds ratio | 95% CI      | P-value |
| Severity of intellectual disability |            |            |         |            |             |         |
| Mild intellectual disability        | Ref.       |            |         | Ref.       |             |         |
| Moderate intellectual disability    | 1.96       | 0.54–8.56  | 0.33    | 2.26       | 0.52–11.58  | 0.29    |
| Severe intellectual disability      | 2.24       | 0.53–10.77 | 0.29    | 2.19       | 0.40–13.31  | 0.37    |
| Profound intellectual disability    | 1.03       | 0.03–14.58 | 0.99    | 2.27       | 0.06–55.90  | 0.62    |
| Ethnicity                           |            |            |         |            |             |         |
| White                               | Ref.       |            |         | Ref.       |             |         |
| Asian                               | 4.03       | 0.62–29.36 | 0.15    | 3.02       | 0.40–25.53  | 0.29    |
| Black                               | 0.91       | 0.29–3.00  | 0.88    | 1.49       | 0.38–6.38   | 0.57    |
| Mixed                               | 0.90       | 0.10–6.50  | 0.92    | 1.94       | 0.12–33.78  | 0.63    |
| Other & unknown                     | 0.61       | 0.11–2.84  | 0.54    | 0.87       | 0.13–5.14   | 0.88    |
| Presence of autism or ADHD          |            |            |         |            |             |         |
| No autism                           | Ref.       |            |         | Ref.       |             |         |
| Autism                              | 4.88       | 1.42–23.41 | 0.02    | 2.96       | 0.58–19.98  | 0.22    |
| No ADHD                             | Ref.       |            |         | Ref.       |             |         |
| ADHD                                | 4.74       | 1.71–13.68 | 0.003   | 2.92       | 0.87–10.30  | 0.086   |
| Modifiable factors                  |            |            |         |            |             |         |
| No challenging behaviour            |            |            |         | Ref.       |             |         |
| Challenging behaviour               |            |            |         | 11.86      | 1.85–235.95 | 0.028   |
| No CAMHS involvement                |            |            |         | Ref.       |             |         |
| CAMHS involvement                   |            |            |         | 5.25       | 1.15–37.82  | 0.051   |
| No mental illness during childhood  |            |            |         | Ref.       |             |         |
| Mental illness during childhood     |            |            |         | 2.98       | 0.82–11.64  | 0.10    |

ADHD, attention-deficit hyperactivity disorder; CAMHS, Child and Adolescent Mental Health Service.

severe mental illness and higher cost care packages, as found in this study. Another possible explanation could be the high comorbidity of other mental illnesses, such as anxiety or mood disorders (not classed as severe mental illnesses in this study), being treated with psychotropic medications in individuals with intellectual disability co-occurring with ADHD.

Similarly, the association between autism and adverse outcomes found in this study fits in with previous studies showing a significant impact of autism on both physical and mental health in individuals with autism and intellectual disability across all ages, along with other functional impairments.<sup>34</sup> Most of these impairments are observed to persist into adulthood.<sup>35</sup> Furthermore, the presence of

**Table 5** Association between childhood factors and care package costs during adulthood

|                                     | Model 1 |           |         | Model 2 |            |         |
|-------------------------------------|---------|-----------|---------|---------|------------|---------|
|                                     | exp(β)  | 95% CI    | P-value | exp(β)  | 95% CI     | P-value |
| Severity of intellectual disability |         |           |         |         |            |         |
| Mild intellectual disability        | Ref.    |           |         | Ref.    |            |         |
| Moderate intellectual disability    | 1.97    | 1.23–3.17 | 0.005   | 2.08    | 1.34–3.22  | 0.001   |
| Severe intellectual disability      | 2.91    | 1.70–4.99 | 0.0001  | 2.92    | 1.79–4.78  | 0.00003 |
| Profound intellectual disability    | 3.24    | 1.45–7.27 | 0.005   | 4.44    | 2.10–9.36  | 0.0001  |
| Ethnicity                           |         |           |         |         |            |         |
| White                               | Ref.    | Ref.      |         |         |            |         |
| Asian                               | 1.03    | 0.49–2.18 | 0.93    | 1.26    | 0.63–2.51  | 0.51    |
| Black                               | 1.56    | 1.01–2.40 | 0.045   | 2.01    | 1.33–3.02  | 0.001   |
| Mixed                               | 2.56    | 1.05–6.26 | 0.039   | 4.29    | 1.89–9.78  | 0.0006  |
| Other/unknown                       | 1.34    | 0.77–2.33 | 0.30    | 1.80    | 1.08–3.00  | 0.03    |
| Presence of autism or ADHD          |         |           |         |         |            |         |
| No autism                           | Ref.    |           |         | Ref.    |            |         |
| Autism                              | 1.57    | 1.07–2.32 | 0.02    | 1.24    | 0.84–1.83  | 0.28    |
| No ADHD                             | Ref.    |           |         |         |            |         |
| ADHD                                | 1.61    | 1.02–2.54 | 0.039   | 1.26    | 0.82–1.93  | 0.29    |
| Modifiable factors                  |         |           |         |         |            |         |
| No challenging behaviour            |         |           |         | Ref.    |            |         |
| Challenging behaviour               |         |           |         | 1.79    | 1.19–2.70  | 0.006   |
| No CAMHS involvement                |         |           |         | Ref.    |            |         |
| CAMHS involvement                   |         |           |         | 0.89    | 0.58–1.36  | 0.59    |
| No mental illness during childhood  |         |           |         | Ref.    |            |         |
| Mental illness during childhood     |         |           |         | 1.63    | 0.99–2.68  | 0.056   |
| Living at a home setting at age 16  |         |           |         | Ref.    |            |         |
| Living in a care setting at age 16  |         |           |         | 4.93    | 1.83–13.28 | 0.002   |
| Not a looked after child            |         |           |         | Ref.    |            |         |
| Looked after child                  |         |           |         | 0.73    | 0.31–1.71  | 0.47    |

ADHD, attention-deficit hyperactivity disorder; CAMHS, Child and Adolescent Mental Health Service.



autism in people with intellectual disability is associated with challenging behaviour.<sup>36</sup> The core symptoms of autism, such as repetitive and restricted behaviours and interests in children with intellectual disability, have been shown to predict challenging behaviours.<sup>37</sup> Therefore, it can be hypothesised that one possible pathway linking autism to adverse outcomes in this study is through the presence of challenging behaviour. The high rate of adverse physical and mental health outcomes found in other studies may explain the significant cost of care associated with autism among people with intellectual disability.

However, these significant associations with autism and/or ADHD disappeared when challenging behaviour during childhood was accounted for in the models. It is likely that the association between ADHD and autism with these outcomes is not direct but may be mediated by challenging behaviours. To test this hypothesis, future studies require three-point longitudinal data. If confirmed, this would underscore the significance of challenging behaviour during childhood as a pivotal variable contributing to long-term adverse outcomes for people with intellectual disability. This connection may have led to increased support needs in adulthood, necessitating higher cost care packages. Furthermore, the increased reliance on psychotropic medications to manage challenging behaviour, as highlighted in previous studies,<sup>38</sup> may explain the high rate of psychotropic medication use in adulthood for those with childhood challenging behaviour.

Increasing severity of intellectual disability was predictive of higher cost packages but did not significantly affect the use of psychotropic medications in the absence of severe mental illness. The increased severity of intellectual disability continued to remain a significant factor associated with higher cost packages in adulthood even after accounting for challenging behaviour. Therefore, the correlation between increasing severity and high-cost care packages in adulthood may not be mediated through challenging behaviour. Our findings align with studies that have shown that the severity of intellectual disability is not significantly associated with increased challenging behaviour,<sup>37</sup> but this contrasts with studies showing the opposite: that increasing severity of intellectual disability predicts challenging behaviour.<sup>39</sup> The higher cost associated with more severe intellectual disability found in this study might simply be attributed to increasing support needs of people with more severe intellectual disability because of low levels of adaptive behaviour skills and limited communication skills.

The role of ethnicity in terms of adverse outcomes was also explored in this study. Studies in non-intellectual disability populations have shown that Black and minority ethnic people are more likely to receive a diagnosis of mental illness compared to White people.<sup>40</sup> Our findings showed that, compared to White people, people with intellectual disability from Black and mixed ethnic backgrounds were more likely to need higher cost packages. However, ethnicity did not play a significant role in psychotropic medication prescribing, even after accounting for challenging behaviour, CAMHS involvement and mental illness during childhood. Studies have shown that people with intellectual disability from Black minority ethnic backgrounds experience worse health outcomes compared to people with intellectual disability from White ethnic backgrounds, owing to indirect causes such as reduced healthcare utilisation.<sup>41</sup> Deprivation may be an additional factor contributing to adverse mental health outcomes among people with intellectual disability from ethnic minority groups.<sup>36</sup> The predominance of Black ethnicity in the study sample might have influenced these findings. However, these results raise the question of whether targeted interventions are needed for children with intellectual disability from ethnic minority backgrounds.

Overall, the key finding highlights the significant association between the presence of challenging behaviour during childhood and both higher cost care and increased psychotropic prescribing in the absence of severe mental illness. It highlights the nature and severity of challenging behaviour, serving as a stark reminder of the important need for various strategies to support and reduce behavioural challenges in children with intellectual disability from an early age.

## Implications

This study established the importance of exploring clinically important outcomes in addition to caseness and mental health symptomatology, which have often been investigated in existing studies. Such outcomes are important to individuals with intellectual disability and their carers in addition to service providers and commissioners. Factors significantly associated with adverse outcomes in adulthood that are identified in this study need further analysis to determine causation. Therefore, direct claims cannot be made about their importance, but this study highlights their associations with adverse outcomes in young adulthood. The findings of this study may help to highlight the importance of challenging behaviour, which is a presentation rather than a diagnosis itself in long-term outcomes, as well as underlying neurodevelopmental disorders such as ADHD, which may drive challenging behaviour. Understanding the importance of associated risk factors may help to actively look for co-occurring neurodevelopmental disorders and develop appropriate screening and diagnostic tools to identify those with neurodevelopmental disorders when people with intellectual disability access mental health services and overcome diagnostic invisibility among children with intellectual disability. The findings underscore the importance of early intervention for prevention or reduction of challenging behaviours in children with intellectual disability and a likely particular focus on children with intellectual disability and additional neurodevelopmental disorders, such as autism and ADHD.

## Limitations

The study's retrospective design suggests that childhood risk factors relied on accurate documentation by clinicians. ADHD is often underdiagnosed among people with intellectual disability, and therefore the number of children with ADHD in this sample may be an underestimation. Only a limited number of risk factors were explored in this study. Numerous risk factors have been shown to contribute to adverse health outcomes in the general population, such as trauma and adverse childhood experiences, but these were not included here because of challenges with retrospectively collecting data from childhood records. Generalisability is limited because of sampling from a single intellectual disability service but participants were ethnically diverse, with most children growing up in relatively deprived households. Finally, wide confidence intervals for challenging behaviour as a predictor of psychotropic medication prescribing suggest measurement instability, which may be because of the small sample size or measurement error.

This study highlighted several significant predictors of adverse outcomes. These risk factors need to be considered by services supporting individuals with intellectual disability. Developing early detection tools for individuals at ultra-high risk for later adverse mental health outcomes in people with intellectual disability is important to reduce the gap in mental health disparities. It is likely to enhance clinical decision-making to expedite preventative interventions during childhood to ensure improved positive future opportunities and increased quality of life.

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## Data availability

The data are not publicly available because of information within the data that could compromise the privacy of participants in this study.

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None.

## Author contributions

B.P., S.M., C.N., V.T. and A.H. – study design and development, data analysis, interpretation and writing the paper. S.M. and C.N. – data collection. A.B. statistical analysis and writing the paper. P.H. and T.V.A. – data analysis, data interpretation and writing the paper.

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## Declaration of interest

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## Ethics statement

The study is a retrospective audit of anonymised data looking at the current clinical practice. This study did not involve any procedures involving human participants. The NHS Health research authority tool (<http://www.hra-decisiontools.org.uk/research/index.html>) was used to confirm that no ethics is needed for this project.

## References

- American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders* (5th edn). American Psychiatric Association, 2013 (<https://psychiatryonline.org/doi/book/10.1176/appi.books.9780890425596> [cited 17 Mar 2021]).
- World Health Organization. *International Classification of Diseases 11th Revision*. World Health Organization, 2021 (<https://icd.who.int/en> [cited 12 Dec 2023]).
- McBride O, Heslop P, Glover G, Taggart L, Hanna-Trainor L, Shevlin M, et al. Prevalence estimation of intellectual disability using national administrative and household survey data: the importance of survey question specificity. *Int J Popul Data Sci* 2021; **6**(1). Available from: <https://ijpds.org/article/view/1342>.
- Totsika V, Liew A, Absoud M, Adnams C, Emerson E. Mental health problems in children with intellectual disability. *Lancet Child Adolesc Health* 2022; **6**(6): 432–44.
- Buckley N, Glasson EJ, Chen W, Epstein A, Leonard H, Skoss R, et al. Prevalence estimates of mental health problems in children and adolescents with intellectual disability: a systematic review and meta-analysis. *Aust N Z J Psychiatry* 2020; **54**(10): 970–84.
- Cooper SA, Smiley E, Morrison J, Williamson A, Allan L. Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. *Br J Psychiatry* 2007; **190**(1): 27–35.
- Hughes-McCormack LA, Rydzewska E, Henderson A, MacIntyre C, Rintoul J, Cooper SA. Prevalence of mental health conditions and relationship with general health in a whole-country population of people with intellectual disabilities compared with the general population. *BJPsych Open* 2017; **3**(5): 243–8.
- Mazza MG, Rossetti A, Crespi G, Clerici M. Prevalence of co-occurring psychiatric disorders in adults and adolescents with intellectual disability: a systematic review and meta-analysis. *J Appl Res Intellect Disabil* 2020; **33**(2): 126–38.
- Emerson E, Bromley J. The form and function of challenging behaviours. *J Intellect Disabil Res* 1995; **39**(Pt 5): 388–98.
- Bowring DL, Painter J, Hastings RP. Prevalence of challenging behaviour in adults with intellectual disabilities, correlates, and association with mental health. *Curr Dev Disord Rep* 2019; **6**(4): 173–81.
- Hassiotis A, Parkes C, Jones L, Fitzgerald B, Romeo R. Individual characteristics and service expenditure on challenging behaviour for adults with intellectual disabilities. *J Appl Res Intellect Disabil* 2008; **21**(5): 438–45.
- Totsika V, Toogood S, Hastings RP, Lewis S. Persistence of challenging behaviours in adults with intellectual disability over a period of 11 years. *J Intellect Disabil Res* 2008; **52**(5): 446–57.
- Cole MG, Dendukuri N. Risk factors for depression among elderly community subjects: a systematic review and meta-analysis. *AJP* 2003; **160**(6): 1147–56.
- Faraone SV, Banaschewski T, Coghill D, Zheng Y, Biederman J, Bellgrove MA, et al. The world federation of ADHD international consensus statement: 208 evidence-based conclusions about the disorder. *Neurosci Biobehav Rev* 2021; **128**: 789–818.
- Cooper SA, Smiley E, Morrison J, Williamson A, Allan L. Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. *Br J Psychiatry* 2007; **190**: 27–35.
- Hsieh K, Scott HM, Murthy S. Associated risk factors for depression and anxiety in adults with intellectual and developmental disabilities: five-year follow up. *Am J Intellect Dev Disabil* 2020; **125**(1): 49–63.
- Scott HM, Haverkamp SM. Mental health for people with intellectual disability: the impact of stress and social support. *Am J Intellect Dev Disabil* 2014; **119**(6): 552–64.
- Ince R, Glasby J, Miller R, Glasby AM. Why are we stuck in hospital? Understanding delayed hospital discharges for people with learning disabilities and/or autistic people in long-stay hospitals in the UK. *Health Soc Care Community* 2022; **30**(6): e3477–92.
- Ailey SH, Johnson TJ, Cabrera A. Evaluation of factors related to prolonged lengths of stay for patients with autism with or without intellectual disability. *J Psychosoc Nurs Ment Health Serv* 2019; **57**(7): 17–22.
- Knapp M, Comas-Herrera A, Astin J, Beecham J, Pendaries C. Intellectual disability, challenging behaviour and cost in care accommodation: what are the links? *Health Soc Care Community* 2005; **13**(4): 297–306.
- Maes B, Broekman TG, Došen A, Nauts J. Caregiving burden of families looking after persons with intellectual disability and behavioural or psychiatric problems. *J Intellect Disabil Res* 2003; **47**(6): 447–55.
- Mehta H, Glover G. *Psychotropic Drugs and People with Learning Disabilities or Autism*. Public Health England, 2019 (<https://www.gov.uk/government/publications/psychotropic-drugs-and-people-with-learning-disabilities-or-autism> [cited 30 Nov 2023]).
- Branford D, Gerrard D, Saleem N, Shaw C, Webster A. Stopping over-medication of people with an intellectual disability, autism or both (STOMP) in England part 2 – the story so far. *Adv Ment Health Intellect Disabil* 2018; **13**(1): 41–51.
- Devapriam J, Rosenbach A, Alexander R. In-patient services for people with intellectual disability and mental health or behavioural difficulties. *BJPsych Adv* 2015; **21**(2): 116–23.
- Solmi M, Radua J, Olivola M, Croce E, Soardo L, Salazar de Pablo G, et al. Age at onset of mental disorders worldwide: large-scale meta-analysis of 192 epidemiological studies. *Mol Psychiatry* 2022; **27**(1): 281–95.
- Cvejic RC, Trollor JN. Transition to adult mental health services for young people with an intellectual disability. *J Paediatr Child Health* 2018; **54**(10): 1127–30.
- World Health Organization. *The ICD-10 Classification of Mental and Behavioural Disorders*. WHO, 1993 (<https://icd.who.int/browse10/2019/en>).
- R Core Team. *R: A Language and Environment for Statistical Computing*. R Foundation for Statistical Computing, 2023 (<https://www.r-project.org/> [cited 10 Dec 2023]).
- Rothman KJ. No adjustments are needed for multiple comparisons. *Epidemiology* 1990; **1**(1): 43.
- Chandler S, Howlin P, Simonoff E, O'Sullivan T, Tseng E, Kennedy J, et al. Emotional and behavioural problems in young children with autism spectrum disorder. *Dev Med Child Neurol* 2016; **58**(2): 202–8.
- Ros R, Graziano PA. Social functioning in children with or at risk for attention deficit/hyperactivity disorder: a meta-analytic review. *J Clin Child Adolesc Psychol* 2018; **47**(2): 213–35.
- Klein RG, Mannuzza S, Olazagasti MAR, Roizen E, Hutchison JA, Lashua EC, et al. Clinical and functional outcome of childhood attention-deficit/hyperactivity disorder 33 years later. *Arch Gen Psychiatry* 2012; **69**(12): 1295–303.
- Perera B, Chen J, Korb L, Borakati A, Courtenay K, Henley W, et al. Patterns of comorbidity and psychopharmacology in adults with intellectual disability and attention deficit hyperactivity disorder: an UK national cross-sectional audit. *Expert Opin Pharmacother* 2021; **22**(3): 1071–8.
- Kinnear D, Rydzewska E, Dunn K, Hughes-McCormack LA, Melville C, Henderson A, et al. Relative influence of intellectual disabilities and autism on mental and general health in Scotland: a cross-sectional study of a whole country of 5.3 million children and adults. *BMJ Open* 2019; **9**(8): e029040.

- 35 Stringer D, Kent R, Briskman J, Lukito S, Charman T, Baird G, et al. Trajectories of emotional and behavioral problems from childhood to early adult life. *Autism* 2020; **24**(4): 1011–24.
- 36 Nicholls G, Hastings RP, Grindle C. Prevalence and correlates of challenging behaviour in children and young people in a special school setting. *Eur J Spec Needs Educ* 2020; **35**(1): 40–54.
- 37 Davies LE, Oliver C. Self-injury, aggression and destruction in children with severe intellectual disability: incidence, persistence and novel, predictive behavioural risk markers. *Res Dev Disabil* 2016; **49–50**: 291–301.
- 38 Hassiotis A, Poppe M, Strydom A, Vickerstaff V, Hall IS, Crabtree J, et al. Clinical outcomes of staff training in positive behaviour support to reduce challenging behaviour in adults with intellectual disability: cluster randomised controlled trial. *Br J Psychiatry* 2018; **212**(3): 161–8.
- 39 Murphy O, Healy O, Leader G. Risk factors for challenging behaviors among 157 children with autism spectrum disorder in Ireland. *Res Autism Spectr Disord* 2009; **3**(2): 474–82.
- 40 Nazroo JY, Bhui KS, Rhodes J. Where next for understanding race/ethnic inequalities in severe mental illness? Structural, interpersonal and institutional racism. *Social Health Illness* 2020; **42**(2): 262–76.
- 41 Magaña S, Parish S, Morales MA, Li H, Fujiura G. Racial and ethnic health disparities among people with intellectual and developmental disabilities. *Intellect Dev Disabil* 2016; **54**(3): 161–72.

