MENTAL HEALTH AND AUTISM SEVERITY OF AUTISTIC YOUTH WHO RECEIVED EARLY INTENSIVE BEHAVIOURAL INTERVENTION

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Abstract

Autism involves social communication difficulties and engagement in restricted and repetitive behaviours and interests. Many autistic youth experience co-occurring mental health conditions. Unfortunately, treatment history is rarely reported in this sample, resulting in ambiguity in the relationship between treatment history and later mental health functioning. Limited research has explored the long-term mental health and education outcomes of Early Intensive Behavioural Intervention (EIBI). The purpose of this study was to describe the mental health, autism symptom severity, medication use, and education outcomes of youth who previously received EIBI. Thirty-two parents completed questionnaires about their child's mental health (i.e., Child Behavior Checklist), autism symptom severity (i.e., Social Responsiveness Scale), education outcomes, and medication use. Scores of mental health measures were higher than the normative sample but lower than scores from other studies of autistic participants. Though uncontrolled, this suggests that autistic youth who received EIBI do not show severe mental health difficulties.

Keywords: autism, mental health, autism severity, long-term outcomes, Early Intensive Behavioural Intervention, Applied Behaviour Analysis

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Autism

Autism is a neurodevelopmental condition involving two main components: 1) difficulties with social communication, and 2) engagement in restricted and repetitive behaviours and interests (American Psychiatric Association [APA], 2022). In North America, approximately 1 in 66 children are diagnosed with autism, with males being four to five times more likely than females to receive a diagnosis (Christensen et al., 2016). Children on the autism spectrum are frequently also diagnosed with an intellectual disability (APA, 2022), which may impact the specific intervention recommended or the expected treatment trajectory. Oftentimes, autistic individuals who are also living with an intellectual disability are not included in research, and therefore, only a subset of individuals on the autism spectrum are represented in the literature.

Mental Health

Mental Health Conditions. Previous research suggests that individuals on the autism spectrum are more likely to experience co-occurring mental health and neurodevelopmental conditions, including anxiety, depressive disorders, attention-deficit/hyperactivity disorder (ADHD), compared to their peers without autism (Costello et al., 2003; Esteves et al., 2021; Gjevik et al., 2011; Gurney et al., 2006; Lai et al., 2019; Mattila et al., 2010; Orinstein et al., 2015; Simonoff et al., 2008; Tsai, 2014). However, the prevalence of co-occurring mental health conditions greatly varies across different studies (Anckarsäter et al., 2006; Tsai, 2014), which may be due to differing ascertainment methods or due to the heterogeneity in presentation (Kantzer et al., 2018). Further, there is a lack of understanding of the impact of cognitive functioning on the occurrence of mental health conditions for individuals on the autism spectrum

(Lai et al., 2019). There are also other factors, such as socioeconomic status, which can impact prevalence rates of co-occurring mental health concerns and access to care (Lai et al., 2019).

It is thought that approximately 70% of people on the autism spectrum have at least one mental health condition, and 50% are diagnosed with more than one mental health condition (Anckarsäter et al., 2006; Albores-Gallo et al., 2017; Gjevik et al., 2011). Based on meta-analyses (i.e., Lai et al., 2019; van Steensel et al., 2011), the prevalence of ADHD (33%; Lai et al., 2019) and anxiety (40%; van Steensel et al., 2011) are much higher for people on the autism spectrum compared to those who are not (7% and 8%, respectively; Costello et al., 2005; Thomas et al., 2015). Further, additional mental health and behavioural conditions, including depressive disorders (12%), obsessive compulsive disorder (10%), and disruptive, impulse control and conduct disorders (10%) are also more prevalent among autistic people than the general population (1-3%, 3%, and 6%, respectively; Adam et al., 2012; Kessler et al., 2005; Merikangas et al., 2022).

It is important to note that the high levels of co-occurrence may also be impacted by the overlap of specific symptoms for particular disorders with the characteristics of autism, the potential of shared underlying mechanisms present across autism and other disorders, and/or the experience of living on the autism spectrum (Amr et al., 2012; Bowers et al., 2015; Brookman-Frazee et al., 2017).

The impact of co-occurring mental health conditions for autistic people is quite robust. It increases the probability that the individual will experience poorer long-term outcomes, such as poorer quality of life and early mortality (Bryson et al., 2008; Close et al., 2015; Croen et al., 2015). Specifically, the presence of ADHD is associated with lower adaptive functioning, executive functioning, and health-related quality of life when compared to autistic people

without ADHD (Davignon et al., 2018; de Bruin et al., 2007; Ghanizadeh et al., 2012; Ghirardi et al., 2018). Moreover, it is thought that anxiety exacerbates autism characteristics, such as social challenges, sensory features, and engagement in restrictive and repetitive behaviours (Gillberg et al., 2016; Gjevik et al., 2011; Gjevik et al., 2015; Goin-Kochel et al., 2008; Gordon-Lipkin et al., 2018; Hallerback et al., 2014). Of concern, the co-occurrence of anxiety in autistic people is also associated with the development of additional mental health conditions, such as depression, which has been demonstrated to lead to increased engagement in aggression, self-harm, oppositional behaviour, and risk of suicide (Hansen et al., 2016; Hofvander et al., 2009; Horowitz et al., 2017; Houghton et al., 2017). While the prevalence of certain severe mental illnesses, such as psychosis (5%) and bipolar spectrum disorders (5%), are not as high compared to the prevalence of other mental health conditions within the autistic population, these conditions are still more common in comparison to the general population (1% and 1%, respectively; Clemente et al., 2015; Joshi et al., 2010; Saha et al., 2005). Further, the prevalence of mental health conditions tends to persist from childhood to adolescence, and rates of co-occurring mental health conditions continue to increase in adulthood, leading to continued impact on the individual's health and quality of life (Joshi et al., 2013).

However, some individuals may experience some of the symptoms of specific mental health conditions, but do not meet full diagnostic criteria or have yet to receive a diagnosis. Therefore, it is helpful to distinguish between mental health conditions and mental health symptoms.

Mental Health Symptoms. In addition to the typical barriers to receiving a mental health diagnosis, such as the wait times to see a psychiatrist and/or psychologist and health disparities, mental health and behavioural conditions are quite challenging to diagnose among autistic people

due to diagnostic overshadowing (i.e., viewing emotional and behavioural symptoms as part of autism; Rosen et al., 2018) or difficulty communicating (Matson & Nebel-Schwalm, 2007; Ozonoff et al., 2005). This is especially relevant for people on the autism spectrum who are also living with an intellectual disability, who may be nonverbal or minimally verbal and unable to describe their symptoms. Therefore, exploring the presence of mental health symptoms results in a broader and more sensitive measure of mental health and behavioural challenges, making it important to explore both conditions and symptoms in the autism population (Vasa et al., 2018) despite both measures being impacted by some of the barriers (e.g., communication challenges).

The Child Behavior Checklist (CBCL; Achenbach & Rescorla, 2001) is a widely used caregiver-report measure that looks at emotional and behavioural problems in youth. Although designed to be used with the general population, it has been evaluated in its use with autistic youth and has been demonstrated to have good reliability, validity, and diagnostic accuracy within the population (Pandolfi et al., 2012, Pandolfi et al., 2014). The two empirically derived broadband scales (i.e., Internalizing and Externalizing) and the eight empirically derived syndrome scales reflect a wide range of mental health symptoms and behavioural problems. The CBCL also includes six DSM-oriented scales that correspond with specific diagnostic categories (Achenbach & Rescorla, 2001).

Previous research that has utilized the CBCL with autistic youth has found that they have higher scores on the Withdrawn/depressed problems, Social problems, and Thought problems syndrome scales, and frequently also higher scores on the Anxious and Attention problems scales, compared to their peers without autism (Bölte et al., 1999; Ooi et al., 2011; Hoffman et al., 2016; Holtmann et al., 2007). For example, Skokauskas and Gallagher (2011) found that, compared to non-autistic peers matched on age and IQ, youth on the autism spectrum scored

significantly higher on the Withdrawn/depressed problems, Social problems, and Attention problems syndrome scales. Autistic youth also scored significantly lower on the Aggressive behaviour scale, which is vital to emphasize given misconceptions regarding autistic people's engagement in aggressive behaviours and acts. Further, when measuring emotional and behavioural problems using the DSM-oriented scales, autistic youth scored significantly higher on Anxiety problems, Somatic problems, and Attention-deficit/hyperactivity problems scales. Moreover, just below half of the youth on the autism spectrum scored in the clinical range on Attention-deficit/hyperactivity problems (44.78%) and Anxiety problems (46.2%) scales.

Similarly, Mazefsky and colleagues (2011) compared the CBCL empirically derived syndrome scores of two different samples of autistic youth without an intellectual disability from different geographical regions and one comparison group of youth with no personal or family history of a neurodevelopmental or mental health disorder. The comparison group was matched on age and IQ with one of the two samples of youth on the autism spectrum. Autistic youth had significantly higher scores across all empirically derived syndrome scores than their neurotypical peers. In addition, the Attention problems, Social problems, and Thought problems scales had the largest discrepancies between the groups of autistic youth and the comparison group. Further, a larger (though highly variable) percentage of scores for autistic youth (10-82%) fell within the clinical range relative to the comparison group (0-5%). This study helps to highlight the increased prevalence of mental health symptoms among autistic youth. However, more research is needed to explore the mental health of autistic youth more broadly, including individuals living with an intellectual disability.

Autism Symptom Severity

Just as exploring the mental health symptoms provides a broader measure of emotional and behavioural problems than diagnoses, it is also helpful to explore autism symptoms rather than just the presence of an autism diagnosis. Especially given the heterogeneity in presentation, exploring the symptom severity allows for a more thorough investigation of autism symptom expression, which can vary widely. The Social Responsiveness Scale–Second Edition (SRS-2; Constantino & Gruber, 2012) is a caregiver- and teacher-report measure that indicates the presence and severity of social impairment specifically for individuals on the autism spectrum. It is also often used as a screener and general measure of autism symptom severity. The SRS-2 has been demonstrated to be a valid and reliable measure of social impairment associated with autism in a natural social context (Aldridge et al., 2012). While the total score is more reliable in terms of interpretation (Bruni, 2014), there are five subscales that provide helpful information about symptom expression (i.e., Social Awareness, Social Cognition, Social Communication, Social Motivation, and Restricted Interests and Repetitive Behavior).

Given that it is frequently used as a screening measure, autistic children and youth do tend to score higher on the measure. Further, individuals with specific co-occurring conditions (i.e., ADHD, anxiety) experience amplified social communication challenges, and therefore, tend to have even higher scores on specific subscales than youth on the spectrum without co-occurring conditions. For example, Factor et al. (2017) found that autistic youth with heightened levels of anxiety displayed higher scores on four of the five subscales (i.e., Social Cognition, Social Communication, Social Motivation, and Restricted Interests and Repetitive Behavior), and those with heightened ADHD symptoms displayed higher scores on two subscales (i.e., Social Communication and Social Awareness). Given the wide-reaching impact social

challenges can have on a person's life, it is important to investigate if, and potentially by how much, these challenges differ for autistic youth who have previously received intervention addressing autism characteristics, such as social challenges.

Medication Use

People on the autism spectrum are frequently prescribed psychotropic medications (Coury et al., 2012; Hsia et al., 2014; Langworthy-Lam et al., 2002; Logan et al., 2012; Memari et al., 2012; Mandell et al., 2008; Rosenberg et al., 2010; Schubart et al., 2013; Spencer et al., 2013), with a higher percentage of autistic children being prescribed medication than what is seen in the general child population (Qato et al., 2018). Aman et al. (2005) reported a substantial increase in the use of a variety of medications for people on the autism spectrum from 1993 to 2001. In addition, Aman and colleagues found that the most common medication used among the sample was selective serotonin reuptake inhibitors to assist with managing perseverative behaviours. Similarly, Oswald and Sonenklar (2007) found that 83% of their sample, which included people under the age of 21 with an autism diagnosis, had at least one drug claim within the year. Furthermore, approximately 70% of children over the age of seven in the sample used some form of psychotropic medication within the year.

Many individuals on the autism spectrum are also reported to take more than one psychotropic medication simultaneously. Although there are certain circumstances where medication is helpful and necessary, it can also result in a variety of adverse immediate (e.g., sedation, weight gain, gastrointestinal problems; McCracken, 2005; Matson & Hess, 2011) and long-term side effects (e.g., diabetes, cardiovascular disease; Stigler et al., 2004; Posey et al., 2008). Therefore, it is helpful to explore medication use within the autism population to determine if there are multiple medications being prescribed, which may result in adverse side

effects, and if there are specific factors that are associated with decreased medication use, such as previous intervention history.

Education Outcomes

There are many education options for children on the autism spectrum, although some may not be financially or geographically accessible to all (e.g., private schools). Since the 1980s, more children on the autism spectrum have been placed within general education classrooms (Ainscow & César, 2006; Gindi, 2020); however, it is thought that the most appropriate teaching environment varies based on certain factors (e.g., age, problem behaviour, cognitive functioning). In a study by Gindi (2020) looking at the classroom placement of autistic youth, the authors found that cognitive functioning significantly impacted classroom placement. The average IQ for students on the autism spectrum included within the general education classroom was significantly higher than the average IQ of children in the special education classroom and those in the specialized school. Likewise, Segall and Campbell (2014) found that cognitive functioning (not diagnostic label) affected classroom placement. Moreover, previous research has also suggested that students who are younger, "higher functioning", and engage in lower rates of problem behaviour are more likely to be placed in general education classrooms (Lyons et al., 2011; Yianni-Coudurier et al., 2008). However, it is important to note that school district policies vary across time and place, which obscures interpretation.

Despite all that is known about the mental health, autism symptom severity, medication use, and classroom placement for autistic youth, treatment history is rarely reported in these studies, making it challenging to identify the relationship between treatment history and mental health outcomes.

Early Intervention

Although there are many interventions available for children on the autism spectrum, interventions based on the principles of Applied Behaviour Analysis (ABA) have been demonstrated to be the most effective (Hume et al., 2021; National Autism Center, 2015; National Research Council, 2001; Odom et al., 2010; OSETT-ASD, 2017). Behavioural interventions can involve a variety of specific approaches and can target an array of different areas, such as improving adaptive behaviour, increasing cognitive functioning, and/or reducing challenging behaviour. One type of behavioural intervention, Early Intensive Behavioural Intervention (EIBI), which is an intensive (i.e., 20-40 hours/week) behaviour analytic intervention designed for young autistic children, has been demonstrated to improve cognitive functioning and adaptive behaviours for children on the autism spectrum (Eldevik et al., 2009; Flanagan et al., 2012; Lovaas, 1987; Perry et al., 2008; Peters-Scheffer et al., 2011), although there has been S (e.g., Eldevik et al., 2006; Perry et al., 2008).

Heterogeneity in EIBI Outcomes

To explore the discrepancies in the findings, additional research has focused on specific child and treatment factors that may influence the effectiveness of behavioural interventions. Based on the current literature, researchers have investigated child factors at the intervention onset that can impact outcomes. Research indicates that EIBI is more effective for children who receive it at a younger age, with these children displaying higher scores post-intervention on cognitive measures (Bibby et al., 2002; Flanagan et al., 2012; Freeman & Perry, 2010; Perry et al., 2011; Perry et al., 2013; Smith et al., 2015), adaptive behaviour measures (Eldevik et al., 2013; Freeman & Perry, 2010; Goin-Kochel et al., 2007; Perry et al., 2011; Smith et al., 2015),

decreased scores on autism severity measures (Perry et al., 2011), and increased performance on non-standardized measures, such as behavioural objectives (Granpeesheh et al., 2009).

Cognitive functioning at the intervention onset has also been demonstrated to account for a significant amount of variance in intervention outcomes (Beglinger & Smith, 2005; Magiati et al., 2007; Perry et al., 2011). More specifically, relatively higher initial cognitive functioning has been associated with better intervention outcomes, including increased cognitive functioning post-intervention (Howlin et al., 2009; Smith et al., 2015), better response to intervention (e.g., increased IQ, language, daily living skills, positive social behaviour, Leaf et al., 2011; Remington et al., 2007), increased acquisition of developmental skills (Ben-Itzchak & Zachor, 2007), higher communication scores on an adaptive behaviour measure (Eldevik et al., 2012; Grindle et al., 2012), higher adaptive behaviour scores (Smith et al., 2015), decreased autism symptom severity scores (Smith et al., 2015), reduced repetitive behaviours (Smith et al., 2015), and less educational support required (Frazier et al., 2021).

Although not many studies have explored the impact of autism symptom severity on EIBI outcomes, those that have suggest that lower autism severity is associated with better intervention outcomes (Ben-Itzchak & Zachor, 2011; Eldevik et al., 2012; Frazier et al., 2021; Perry et al., 2011; Sallows & Graupner, 2005). In addition, limited research has also explored the impact of additional medical conditions, although Eriksson et al. (2013) found that the presence of additional medical conditions was associated with referral to invention at an earlier age but poorer intervention outcomes (Eriksson et al., 2013). Researchers have also explored initial response to intervention and response to reinforcers, with better initial response (e.g., in initial weeks of treatment) associated with better outcomes (Goin-Kochel et al., 2007; Klintwall & Eikeseth, 2012; Smith et al., 2000; Weiss, 1999).

Moreover, specific intervention factors have also been demonstrated to positively impact results, including increased quality (e.g., Långh et al., 2017; Långh et al., 2022) and quantity, such as intensity (Granpeesheh et al., 2009) and duration (Luiselli et al., 2000) of the intervention. In addition, supervision factors, such as number of supervision hours (Reichow & Wolery, 2009) and different supervisor credentials (Dixon et al., 2016), have also been demonstrated to impact the effectiveness of behavioural interventions. Although these specific child and treatment factors have been identified to be influential on the effectiveness of EIBI, additional research is required as there is still some ambiguity and contradictory findings for some factors, as well as methodological limitations in many of the studies. Despite the strong evidence that EIBI is effective in addressing cognitive and adaptive functioning, little research has explored the impact of EIBI on other outcome measures, including mental health, autism symptom severity, medication use, and education outcomes.

Mental Health Outcomes

Although EIBI programming frequently targets specific skills that are known to be associated with emotional and behavioural problems (e.g., emotion regulation, problem behaviour; Campbell-Sills & Barlow, 2007; Hannesdottir & Ollendick, 2007; Ladouceur et al., 2005) limited research, to our knowledge, has explored mental health as an immediate outcome variable of the intervention. This could potentially be due to the young age of children post-intervention, as the presence of mental health symptoms is associated with increased age (Lai et al., 2019). Of the limited research that has explored mental health outcomes for autistic children who received EIBI, it appears those who received EIBI have lower scores on the CBCL relative to autistic children who received a different intervention (e.g., Fava et al., 2011). Further, those

who received EIBI demonstrated higher scores on scales associated with an autism profile (e.g., Thought problems; Sallows & Graupner, 2005)

Autism Symptom Severity Outcomes

Previous research exploring the impact of EIBI on autism symptom severity suggests that EIBI leads to a significant decrease in symptom severity (e.g., Flanagan et al., 2011; Freeman & Perry, 2010; Perry et al., 2008), with some studies indicating clinically significant changes, including changes in participants' diagnostic severity category (e.g., mild/moderate range pre-intervention to non-autism range post-intervention; Freeman & Perry, 2010). Further, some studies have included more circumscribed measures addressing autism-specific behaviours, such as measuring and demonstrating changes in joint attention, social behaviour, play skills, and engagement in restricted and repetitive behaviours. For example, MacDonald et al. (2014) explored the impact of EIBI on autism-specific behaviours as measured by the Early Skills Assessment Tool (MacDonald et al., 2006), finding that EIBI led to a decrease in autism-specific behaviours immediately following intervention. Therefore, the immediate impact of EIBI on decreasing autism symptom severity is well-documented in the literature immediately following cessation of the intervention.

Medication Use Outcomes

No researchers to our knowledge have explored the immediate impacts of EIBI using medication use as an outcome variable. Again, perhaps this is due to the young age of children post-EIBI and given that we know medication use among the autistic population increases as children age (Oswald & Sonenklar, 2007).

Education Outcomes

Given that EIBI targets prerequisite skills required to learn in the general education environment (e.g., attending skills), and factors that impact classroom placement (e.g., cognitive functioning), it is not surprising that children who receive EIBI are more likely to be placed in general education classrooms relative to those in a comparison group who either received a low-intensity ABA intervention or a different intervention (e.g., Lovaas, 1987; Waters et al., 2020). Moreover, children who receive EIBI tend to score higher on standardized measures of academic achievement relative to a comparison group of autistic children who received a different intervention (e.g., Smith et al., 2000).

EIBI Long-Term Outcomes

Despite many studies demonstrating the benefits of EIBI for children on the autism spectrum immediately following completion of the intervention, a limited number of studies have explored the long-term outcomes of those who received the intervention. McEachin et al. (1993) conducted a follow-up study of the seminal Lovaas (1987) sample five years following participation in EIBI. They found that, five years following completion of EIBI, those who had received EIBI had significantly higher IQ and adaptive behaviour scores than those in two comparison groups. Further, almost half of those who had received EIBI were placed in a regular education classroom in comparison to none of those in the comparison groups.

Similarly, Kovshoff et al. (2011) explored the long-term benefits of EIBI for autistic children by comparing those who received parent-implemented EIBI, clinic-based EIBI, and a control group. Two years following the intervention, more children who had received either EIBI intervention were in general education classrooms compared to those in the comparison group; however, there were no significant differences in IQ or adaptive behaviour.

Two studies have examined longer-term outcomes following EIBI. Smith et al. (2021) conducted a 10-year follow-up assessment of 19 children who received EIBI as young children. Immediately following the intervention, children displayed decreased autism symptom severity, along with increased cognitive and adaptive standard scores, and these gains were maintained at follow-up.

Similarly, Perry et al. (2019) followed up 21 children (at age 13-20 years) who had received EIBI as young children, 10 years following the end of the intervention. Immediately following EIBI, at about age 6, children were grouped into three outcome categories: good, medium, and poor. At the 10-year follow-up, placement in these groups remained fairly consistent (e.g., those in the good outcome group immediately following EIBI remained in the good outcome group at the 10-year follow-up). Further, participants demonstrated increases in skill level (age equivalent scores) and stable or slightly declining standard scores over time.

Although these studies provide helpful information regarding the long-term benefits of EIBI, it is important to note the relatively small sample size and the lack of a control group when interpreting these findings. Further, the sample representativeness may be questionable as well as the possible bias of the authors in favour of EIBI.

Typically, when documenting the outcomes of EIBI, measures used involve cognitive and adaptive behaviour standard scores, autism severity scores, and, less often, placement in school (e.g., general vs special education teaching). However, it is important to also consider the impact of EIBI on mental health conditions and symptoms, especially given that children on the autism spectrum are at increased risk for experiencing mental health challenges compared to those without autism. Very few studies have explored the mental health of children on the autism spectrum who previously received EIBI. Moreover, it has recently been suggested that previous

participation in ABA interventions, such as EIBI, is correlated with increased post-traumatic stress disorder symptoms in autistic adults (Kupferstein, 2018). Given the substantial methodological and conceptual flaws in Kupferstein's study design (Leaf et al., 2018), these results should be interpreted with extreme caution. However, these findings, together with recent social media postings, highlight the importance of better understanding the long-term mental health outcomes of youth who participated in EIBI.

Mental Health Outcomes

In terms of mental health conditions, only one of the follow-up studies mentioned above noted if participants had co-occurring conditions at follow-up. Smith et al. (2021) noted that participants did not have any co-occurring mental health or behavioural conditions; however, no information was provided on the presence of mental health or behavioural symptoms.

To further explore the long-term mental health symptoms of EIBI recipients, Koudys et al. (2021) investigated the mental health of a subset of the participants who participated in the Perry et al. (2019) study. The study included data from 12 male participants (those who were able to provide self-reports on mental health questionnaires), who had received two years of EIBI starting around 3 years of age, along with data from their mothers and their teachers. Koudys et al. (2021) found that most of the participants were not experiencing mental health difficulties (approximately 70%); however, mean Internalizing scores, as rated by parents and teachers, though not the youth themselves, were significantly higher than those of the normative sample. Without the inclusion of a control group, it is impossible to determine whether these Internalizing scores are higher or lower for those who received EIBI compared to autistic youth who did not receive EIBI. It may be that Internalizing scores are just higher for autistic

individuals, regardless of receiving EIBI or not, which would be expected based on the autism and internalizing behaviours literature reviewed above (e.g., Lai et al., 2019).

Autism Symptom Severity Outcomes

A few of the follow-up studies explored autism symptom severity. While Rivard et al. (2018) found that participants' scores increased from post-intervention to follow-up, Smith et al. (2021) and Perry et al. (2019) found that participants' scores decreased from pre- to post-intervention, and this decrease was maintained at follow-up. Further, Perry et al. (2019) found that participants' autism symptom severity scores continued to decrease over time, and these decreases were clinically significant. However, this finding was based on a single score on a direct behavioural observation measure of autism symptoms. No studies have examined more nuanced symptoms of autism based on standardized parent-report measures.

Medication Outcomes

Smith et al. (2021) was the only follow-up study that explored the use of psychotropic medication and found no participants were taking any. While this information is promising, it is important to note the lack of control group. However, when comparing these findings to the general statistics of psychotropic medication use among autistic people, these findings are encouraging.

Education Outcomes

Previous research has demonstrated the immediate and long-term impact of EIBI on academic performance, education placement, and required educational support. Of the follow-up studies that included education outcomes (i.e., Kovshoff et al., 2011; McEachin et al., 1993), results suggest that typically more children from the EIBI groups are placed in general education classrooms compared to few or none of the children in the comparison groups. Perry et al. (2019)

found that, at the 10-year follow-up, there was a wide range in terms of academic outcomes and classroom placement (43% receiving specialized teaching, 28% receiving general education teaching, and 29% receiving a combination).

Present Study

Little research has explored how youth who received EIBI as children are functioning across domains over time. Most studies focus specifically on cognitive and adaptive standard scores and do not consider mental health, autism symptom severity, medication use, and educational outcomes. Further, although it is well established that individuals on the autism spectrum are at an increased risk of experiencing mental health challenges, relative to non-autistic peers, limited research has explored whether this is also accurate for those who have received EIBI as young children. Therefore, the purpose of the present study was to explore a range of outcomes including chiefly the mental health and autism severity of autistic youth who received EIBI as young children.

More specifically, the research objectives were:

1. To describe mental health (e.g., internalizing and externalizing symptoms), autism symptom severity (e.g., social communication, restrictive interests and repetitive behaviour), education outcomes (i.e., classroom placement), and medication use for a sample of autistic youth who previously received EIBI.
2. To examine whether there are differences in mental health and autism symptom severity for children who previously received EIBI compared to (a) the normative and at-risk samples from manuals for the standardized measures and (b) autistic youth in general using data from peer-reviewed published research studies.

Method

The present study involved secondary data analyses using data from the Simons Foundation for Autism Research Initiative (SFARI). Specifically, we explored the Simons Simplex Collection (SSC) and long-term follow-up data involving a subset of these participants; therefore, we utilized longitudinal data. The study is primarily descriptive. As there is no comparison group available, scores on standardized measures were compared to normative groups or findings from peer-reviewed studies.

Participants

The SSC dataset involves data collected from 2,600 simplex families (i.e., one child with autism, parents and siblings do not have autism). Participants were between the ages of 4 and 18 years at the time of the initial data collection. All participants met criteria for autism but were excluded if they displayed severe sensory impairments, motor difficulties, genetic syndromes, and medical histories. The sample includes individuals with and without an additional diagnosis of intellectual disability and includes a larger sample of males compared to females, as expected based on diagnostic statistics.

Participants were recruited from 12 university-affiliated sites in Canada and the United States. Recruitment for the initial timepoint of data collection ended in 2011 and the follow-up assessments were completed in 2015. Study procedures were approved by the university ethics boards, and parents/caregivers provided consent while children provided assent. Participation in the initial data collection required 4.5 to 7 hours of parents' time, which involved completing parent-report measures, and 2.5 to 4 hours of their child's time, which included completion of various diagnostic and behavioural measures. All participants were informed that participating was voluntary, and they could withdraw from the study at any time without consequences. All

participants were compensated with Visa gift cards following participation in the study. De-identified data were stored in a secured central databank. The purpose of the data collection was primarily for researchers to be able to access a large sample of simplex cases to explore genetic factors related to autism, along with a wide range of diagnostic, developmental, and demographic variables. It was not a treatment-oriented study, but basic information was collected about what treatments children had received. Thus, there is no risk of bias in the sample in terms of the researchers' commitment to EIBI.

A total of 440 families participated in a Follow-up Study. The follow-up data collection was online only. For the present study, we included participants from the dataset who completed the initial and follow-up measures, whose parents reported their child receiving EIBI for at least 12 months between 2 and 5 years of age. In total, there were 42 participants (84.4% male and 15.6% female), though numbers varied for specific measures. Most participants received EIBI in both school and home settings (42.9%); however, some participants received EIBI either in school settings (16.7%) or at home (38.1%). The average duration, which included the total number of weeks participants received EIBI for at least 20 hours per week, was 99.81 weeks. The average total hours of EIBI, defined as the number of hours per week the participant received EIBI multiplied by the duration of the intervention was 7536.93 hours. Participants' FSIQ varied, with 45% of participants' FSIQ at time 1 falling below 70, and 55% of participants with FSIQ scores equal to or greater than 70 (see Figure 1). Descriptive information about the participants is included in Table 1.

Measures

Child Characteristics

Adaptive Behaviour. The Vineland-II, Parent/Caregiver Interview Form (Sparrow et al., 2005) measures both adaptive and maladaptive behaviour in individuals between birth and 90 years of age. The measure includes four domains: Communication, Daily Living Skills, Socialization, and Motor Skills (only for children under 6 years). The measure has high interrater and inter-interviewer agreement, split-half reliability for the total score and composites, and test-retest reliability (Sparrow et al., 2011).

Cognitive Functioning. To measure cognitive functioning, an age- and developmentally appropriate measure was used given the wide range of cognitive functioning across the sample, including The Differential Ability Scales–Second Edition (DAS-II; Elliott, 2007), Mullen Scales of Early Learning (MSEL; Mullen 1995), Wechsler Intelligence Test for Children–Fourth Edition (WISC-IV; Wechsler, 2003), and the Wechsler Abbreviated Scale of Intelligence (WASI; Wechsler 1999). Therefore, cognitive functioning scores included full scale IQ scores (M=100, SD=15) via the WISC-IV and the WASI, Early Learning Composite standard scores from the MSEL (M=100, SD=15), and General Conceptual Ability standard scores (M=100, SD=15) from the DAS-II. For some children, a ratio IQ score (i.e., mental age/chronological age x 100) was the only available cognitive measure.

Outcome Measures

Mental Health.

Mental Health Conditions. Participants' parents provided information at the time of the follow-up assessment regarding any co-occurring disorders (e.g., anxiety).

Mental Health Symptoms. The CBCL (Achenbach, 2004) and the Adult Behaviour Checklist (ABCL; Achenbach, 2004) are components of the Achenbach System of Empirically Based Assessment (ASEBA), which is used to detect emotional and behavioural problems in youth and adults. These measures include empirically based syndrome scales, which slightly differ on the ABCL (i.e., Anxious/depressed, Withdrawn, Somatic complaints, Thought problems, Attention problems, Rule breaking behavior, Aggressive behavior, and Intrusive) and CBCL (i.e., Anxious/depressed, Withdrawn/depressed, Somatic complaints, Social problems, Thought problems, Attention problems, Rule breaking behavior, and Aggressive behavior). These scales were developed based on factor analyses across parent, teacher, and youth/adult self-report forms. Both the ABCL and the CBCL also include DSM-oriented scales, which also differ for the ABCL (i.e., Depressive problems, Anxiety problems, Somatic problems, Avoidant personality problems, Attention-deficit/hyperactivity problems, and Antisocial personality problems) and CBCL (i.e., Depressive problems, Anxiety problems, Somatic problems, Attention-deficit/hyperactivity problems, Opposition defiant problems, and Conduct problems). Scores can be categorized into specific ranges, including typical, borderline, and clinical ranges for both the broadband (i.e., Total problems, Internalizing, Externalizing; clinical $T > 63$, borderline $T = 60\text{-}63$, typical $T < 60$) and scale scores (i.e., syndrome and DSM-oriented scales; clinical $T > 69$, borderline $T = 65\text{-}69$, typical $T < 65$).

The CBCL includes 113 items and the ABCL includes 118 items, and both measures include the use of a 3-point Likert scale (0 = *absent*, 1 = *occurs sometimes*, 2 = *occurs often*). The CBCL is specifically for children between the ages of 6 to 18 years of age and the ABCL is designed for adults over the age of 18 years, and both are to be completed by a parent or caregiver. The CBCL and ABCL have good psychometric properties, including good test-retest

reliability, internal consistency, content validity, criterion-related validity, and construct validity. For the present study, we will be using *T* scores from the parent-report data.

The CBCL normative sample involves 1753 children, with 52% identifying as boys and the majority of the sample is considered middle class. In total, 72% of the CBCL surveys were completed by mothers, with fathers completing 23%, and the remaining 5% reported as being completed by other. Children who were reported to receive mental health services, special education services, substance use services were excluded from the normative sample (Achenbach & Rescorla, 2007).

The CBCL referred sample included 1605 children with a referral for a behavioural or emotional problem. The mean age of the sample was 11.7 years, and 53% identifying as boys. The mean socioeconomic status (rated using a 3-point scale) is considered middle class, and 57% of the sample is white. For majority of the sample, the mother completed the measures (62%; Achenbach & Rescorla, 2007).

Autism Symptom Severity. One of the main outcome measures was the SRS-2 (Constantino & Gruber, 2012) which measures autism symptom severity. The SRS-2 is a questionnaire that indicates the presence and severity of social impairment specifically for individuals with autism. The measure includes a total score along with five different subscales: Social Awareness, Social Cognition, Social Communication, Social Motivation, and Restricted Interests and Repetitive Behaviours. The SRS-2 has 65 items and utilizes a 4-point Likert-type scale (1 = *Not True,* 2 = *Sometimes True*, 3 = *Often True*, 4 = *Almost Always True*). Scores can be categorized into different ranges, including typical (*T* score < 60), mild (*T* score = 60-65), moderate (*T* score = 66-75), and severe (*T* score > 75). The measure can be completed by parents or teachers for individuals between the ages of 2 to 18 years of age. The measure has been

demonstrated to have good psychometric properties, including good internal consistency (r = .95), adequate interrater reliability (r = .77 and .61), content validity, and construct validity (Bruni, 2014; Constantino & Gruber, 2012).

The school-aged standardization sample for the SRS-2 includes 1,012 children between the ages of 4 and 18 years. There is a range in parental education level and geographical region (within the United States). Ethnic representation is similar to national figures, with 59% of the sample identifying as white. Approximately half of the sample (49%) are male. It is unclear whether the standardization sample excluded children with mental health and neurodevelopmental conditions.

Medication Use. Participants' parents provided information at the time of the follow-up assessment regarding their child's medication use (i.e., yes or no, which medication).

Education Outcomes. Participants' parents provided information at the time of the follow-up assessment regarding their child's school (i.e., private, public, other) and classroom placement (i.e., special education teaching, general education teaching, combination).

Results

Objective 1: Descriptives for the Outcome Measures

Mental Health

Mental Health Conditions. Thirty-three parents provided information on their child's medical history, including current diagnoses (see Table 2). No parents reported their child to have a diagnosis of schizophrenia or bipolar disorder. The survey given by SFARI did not ask parents if their child received a diagnosis for externalizing disorders, such as conduct disorder or oppositional defiant disorder.

Mental Health Symptoms. Mental health symptoms were explored using the CBCL (*n*=30) or ABCL (*n*=3; see Table 3). The average for all broadband and narrowband scores fell within the non-clinical range (see Figures 2-4), although the group means for Thought problems and Attention problems were in the borderline range. Further, when exploring participants' scores on an individual level (see Figures 5-7), the scores for most participants fall within the non-clinical range. Moreover, most participants' scores fall within the normal range on externalizing behaviour scales (i.e., Externalizing, Aggressive behaviour, Rule-breaking behaviour, Conduct problems, Oppositional defiant problems). More participants' scores fall within the clinical range on scales associated with an autism profile (e.g., Thought problems, Attention problems).

When investigating the classifications of individual scores, the percentage of participants whose scores fell within the borderline and clinically elevated range is outlined in Table 4 and Figures 8-10. It can be seen that about one-quarter of the sample scored in the clinical range for Total Problems and Internalizing but very few for Externalizing. On specific subscales, most participants fell within the normal range, with Attention-Deficit/Hyperactivity, Social problems, Thought problems, and Attention problems having a higher percentage of individuals in the borderline and clinical ranges compared to the other subscales.

Autism Symptom Severity

In total, 36 parents completed the SRS-2 about their child. Descriptive data from the SRS-2 completed by the parents is included in Table 5. Mean scores for the total and subscales fall within the clinically significant range (i.e., over 60; see Figure 11), specifically in the moderate range (i.e., between 66 and 75). The individual scores (see Figure 12) demonstrate

variability in autism symptom presentation, with some participants having consistently low or high scores across the subscales, and others displaying variability across subscales.

Looking at the classifications of individual scores, the percentage of participants whose scores fell into the typical, mild, moderate, and severe categories is outlined in Table 6 and Figure 13. Most participants' scores fell within the clinical range, as anticipated given that these individuals do have an autism diagnosis. The specific dispersion of scores across categories ranges across subscales, with some scales having more scores that fall within the typical and mild range (Social motivation, Social cognition) than others (Total, Restricted interested and repetitive behaviours, Social communication, Social awareness).

Medication Use

Parents provided information about their child's medication use. Half of the parents reported that their child was taking medication (n = 18; 50%). The percentage of the EIBI sample's use of specific medications is displayed in Figure 14, although there was no information provided regarding what the medication was intended to treat.

Education Outcomes

In total, 32 parents provided information about their child's education, including the type of school their child attends (see Table 7) and information about classroom placement (see Figure 15). Most students attend a public school, and regardless of school type, the majority receive special education teaching for part or all of the day. One parent indicated that their child no longer attends school (given their child's age), and therefore, their information is not included below.

Objective 2: Comparing the EIBI Sample to the Normative Sample

We were interested in exploring if and how the mental health and autism symptom severity outcomes for autistic youth who received EIBI differed from normative samples for standardized measures (i.e., CBCL and SRS-2). Further, we were interested in exploring if and how mental health and autism symptom severity outcomes differed for autistic youth who previously received EIBI to autistic youth more broadly. Given that the norms of youth on the autism spectrum were not outlined in the manuals for the CBCL and SRS-2, we included samples from peer-reviewed published research studies that included the same measures and a broader autism sample (i.e., did not receive EIBI as part of the study) as a comparison group.

Mental Health

Comparing Means.

CBCL Normative Sample. One sample *t*-tests were used to explore whether the ABCL and CBCL outcome measures for the EIBI sample differed significantly from the normative sample (*T* score = 50, *SD* = 10). We used a Bonferroni correction to account for running multiple *t*-tests (.05/23 *t*-tests = .002), and Hedge's *g*, which is a measure of effect size, outlining how much one group differs from the other (small = 0.2, medium = 0.5, large = 0.8). The results of the *t*-tests are included in Table 8. The EIBI sample had significantly *higher* scores on all the CBCL and ABCL scores, except for the broadband Externalizing scores.

Mazefsky et al. (2011)'s Sample. We were also interested in examining how these group means compared to the group means of people on the autism spectrum more broadly. We compared the CBCL group means of the EIBI sample to the autism samples included in the Mazefsky and colleagues (2011) study. The Mazefsky and colleagues' study included three samples from two sites. Sample 1 included 78 youth on the autism spectrum from Pennsylvania.

Sample 2 included 67 age- and IQ-matched neurotypical youth who were also from Pennsylvania. Sample 3 included 30 youth on the autism spectrum from Virginia. The mean scores for the neurotypical sample are very similar to the normative sample means. Although not tested statistically, the group means are lowest for the neurotypical sample, and the EIBI sample has consistently *lower* means than both autism samples (see Figure 16).

Comparing Proportion in Clinical Range.

CBCL Referred Sample. When comparing the percent of the EIBI sample who fell within the "deviant" range (includes both clinical and borderline range) with the referred sample in the ASEBA Manual, the percentages in the clinical ranges are *lower* for the EIBI sample across all domains except for Thought problems scores (see Figures 17-19). We used chi-squared analyses to determine if this difference was significant. The percent of individuals in the EIBI group whose score fell within the clinical range differed significantly from the percent of individuals from the referred sample for all scales except for the attention scales (i.e., Attention problems and Attention-deficit/hyperactivity scale) and Thought problems scale (see Table 9). For both attention scales (i.e., Attention-deficit/hyperactivity problems and Attention problems), there was no significant difference between the referred sample and the EIBI sample. For the Thought problems scale, there was a significantly *higher* percentage of individuals in the EIBI group in the clinical range than in the referred sample.

Mazefsky et al. (2011)'s Sample. We were also interested in looking at how these percentages in the clinical ranges compared to autistic people and a non-referred sample. Therefore, we compared the percent of the EIBI sample who fell within the clinical ranges on the CBCL syndrome scales with the autism (both autism samples within the study combined) and the neurotypical sample from Mazefsky et al. (2011). The percentage of individuals in the clinical

ranges is lowest for the neurotypical sample; however, the percentage in the clinical ranges is *lower* for the present EIBI sample than the autism sample across all domains (see Figure 20).

Autism Symptom Severity

Comparing Means.

SRS-2 Normative Sample. One sample *t*-tests were used to explore whether the SRS-2 scores for the EIBI sample differed significantly from the normative sample (*T* score = 50, *SD* = 10). The results of the *t*-tests are included in Table 10. The EIBI sample had significantly *higher* scores on all measures. Further, comparisons of the specific normative sample groups by sex included in the manual with the EIBI sample are displayed in Figure 21, displaying that the EIBI sample had consistently *higher* autism symptom severity scores than the normative sample.

SRS-2 Study Samples. We also explored the difference between different autism populations, including those from different geographical regions, in relation to the EIBI sample. Figure 22 includes a comparison of raw SRS-2 scores of the EIBI sample with samples from different studies conducted internationally that involved participants on the autism spectrum. It is important to note that the treatment history of the participants included within the study samples is unknown. Although not tested statistically, the current EIBI sample appears to have *lower* SRS-2 total scores than all other studies, except for Roeyers et al. (2011) which included autistic youth from the Netherlands.

Kalb et al. (2011)'s Sample. We also compared the raw scores on the SRS-2 subscales from the EIBI sample to the Kalb et al. (2011). The Kalb and colleagues (2011) study involved 2,720 youth on the autism spectrum from a US-based online research database (i.e., Interactive Autism Network). Given the large and diverse sample included in the study, and that this study was the only study we could find that reported subscale scores, the sample was a fitting

comparison group. Although not tested statistically, the group means are *lower* for the EIBI sample than the Kalb et al. (2011) sample (see Figure 23).

Discussion

The aim of the current paper was to (a) describe mental health, autism symptom severity, education outcomes, and medication use for a sample of autistic youth who had previously received EIBI as young children, and (b) examine whether there are differences in mental health and autism symptom severity for children who previously received EIBI compared to normative samples and to other samples of youth on the autism spectrum. Our sample included autistic youth whose caregivers reported that their child previously received EIBI for an average of 1.9 years, approximately 9 years before completing the follow-up measures. The sample included youth with diverse child characteristics, including IQ and adaptive functioning scores, signifying that some participants would also meet criteria for an intellectual disability while others would not.

Based on the information provided by parents at the follow-up assessments, the prevalence of most mental health conditions, including depressive disorders (3%), anxiety (24%), and ADHD (24%), was *lower* for the EIBI sample than the prevalence reported in the literature for the autism population, in general (12%, 40%, and 33%, respectively). The prevalence of obsessive compulsive disorder (15%) was slightly *higher* than that seen in the general autism population (10%). Further, the prevalence of multiple mental health conditions was much *lower* for the EIBI sample (18%) than the general autism population (50%).

For mental health symptoms measured using the ABCL and CBCL, the average for all broadband and narrowband scores fell within the non-clinical range. However, the means for Thought and Attention problems were higher than other scores, which is consistent with the

autism and mental health literature (Bölte et al., 1999; Hoffman et al., 2016; Holtmann et al., 2007; Ooi et al., 2011) but were still not in the clinical range. Further, when exploring the ABCL and CBCL scores on an individual level, most participants' scores did not fall within the clinical range, especially on Externalizing scores. When exploring the categorization of ABCL and CBCL scores, most participants' scores fell within the normal score range across broadband and narrowband scores, with a larger percentage falling within the clinical range for the scales associated with an autism diagnosis (e.g., Thought problems, Attention problems).

It may also be anticipated that youth in our sample would have higher Externalizing scores given that many autistic people meet criteria for externalizing disorders, such as oppositional defiant disorder (25% prevalence; Gadow et al., 2008); however, Externalizing scores were comparable to the norms. Although we cannot conclude that the lower Externalizing scores are a result of EIBI, it is interesting to note that these scores are similar to the normative sample and lower than some other studies measuring externalizing behaviours in autistic people in general using the CBCL (e.g., Fombonne & Zuckerman, 2021). It is also important to note the low levels of externalizing behaviours given the misconception that may be held by the public, based on highly publicized but rare situations, that autistic people are aggressive and violent.

When comparing CBCL scores with the normative sample, the EIBI sample had significantly *higher* scores, although, these scores were not in the clinically significant range. Therefore, these scores indicate that, although the EIBI sample did display *higher* mental health symptoms, especially on scales associated with an autism diagnosis, these means scores were not high enough to indicate clinical concern, which aligns with previous research findings (i.e., Koudys et al., 2021). Further, when we compared the CBCL scores from the EIBI sample with other samples of autistic youth (Mazefsky et al., 2011) visually, the EIBI group had consistently

lower scores across all scales, suggesting that the youth who previously received EIBI may have decreased mental health symptoms in comparison to autistic youth more generally.

Further, we explored the percentage of the EIBI sample whose score fell within the clinical and borderline range with the CBCL referred sample and found that the percentages in the clinical ranges are *lower* for the EIBI sample across all domains except for Attention-deficit/hyperactivity, Thought problems, and Attention problems scores. When we compared these percentages of youth from the EIBI sample in the clinical range with the percentages of neurotypical and autistic youth from the Mazefsky et al. (2011) sample within the clinical range, the percentages are *lower* for the EIBI sample than the published autism sample, but *higher* than the neurotypical sample. These findings are consistent with the autism and mental health symptom literature, indicating that youth on the autism spectrum experience greater mental health symptoms than neurotypical youth. However, these findings also suggest that there is no evidence that youth who participated in EIBI are experiencing poorer mental health outcomes relative to the general autism population. In fact, across most measures, the mental health symptoms scores of the EIBI sample are *lower* than scores from a range of studies including general autism samples.

We also explored autism symptom severity as measured by the SRS-2 completed by parents. Group means for the autism symptom severity scores fell within the clinical range (moderate), with individual scores demonstrating variability in symptom presentation across subscales. Given that the sample includes individuals with a formal autism diagnosis, and one of the defining features of autism is social-communication deficits, it is not unexpected that participants' scores would fall within the clinical range. However, the categorization of scores across subscales also demonstrates the variability in presentation and severity across participants,

with participants falling within the typical, mild, moderate, and severe ranges across the total scale and all subscales. Scores on the SRS-2 for the EIBI sample were significantly *higher* than the normative sample; however, these scores were *lower* than the scores included in most other studies that involved individuals on the autism spectrum. Therefore, these findings may suggest that youth who receive EIBI experience less social impairment years later, which has been demonstrated to impact quality of life (Kuhlthau et al., 2010).

Regarding medication use, the percentage of those taking medication (50% as reported by parents) is much *higher* in the EIBI sample than that seen in typically developing children (20%; Qato et al., 2018), which is not surprising given the increased medication use typically seen in autistic samples, especially as youth age and if they have co-occurring diagnoses (Jobski et al., 2017). However, the percentage of those taking medication in our EIBI sample is *lower* than the percentage stated for the general autism population (83%; Oswald & Sonenklar, 2007). Further, none of the parents reported that their child is prescribed multiple psychotropic medications, which is quite common in the general autism population (Lake et al., 2014). Unfortunately, no information was provided on the purpose of the medication, such as whether the medication was prescribed to help with mental health symptoms, autism characteristics (e.g., rigidity), or other concerns.

Youth from our sample received a variety of different educational placements and teaching styles, including 26% receiving general education teaching, 42% receiving special education teaching, and 32% receiving a combination of both. We were unable to find comparison statistics in the literature to explore whether these rates differ from the percentages seen in the general autism population. However, we are aware that there are many child factors impacting classroom placement that are targeted using EIBI (e.g., cognitive functioning), and that, in previous studies,

more children who received EIBI were placed in general education classrooms than children in the comparison group (e.g., Kovshoff et al., 2011; McEachin et al., 1993), but we are unsure if our findings are consistent with these. However, we are also aware that there are external factors that can impact classroom placement as well (e.g., geographical and financial restrictions, teaching styles offered by the child's school, educational philosophies regarding inclusion, etc.).

Strengths

The methodology of the present study has many notable strengths. First, the study included standardized measures that are not typically included in EIBI research, particularly regarding mental health. Very few studies have explored mental health as an outcome variable, with even fewer looking at mental health symptoms in addition to conditions. Further, we included other variables that are not often explored in the EIBI literature, including classroom placement and medication use. The study also involved a more neutral dataset. For example, the Koudys et al. (2021) study involved a sample of individuals who participated in EIBI, specifically within Ontario, as part of a research project by researchers who might be considered biased in favour of EIBI. The present dataset includes individuals who happen to have received EIBI from a variety of providers in different geographical regions. Further, the participants in the present study were not specifically recruited for an EIBI research study, which may attract a specific subset of EIBI recipients, although participants were from middle to upper socioeconomic status households and simplex families. Moreover, the sample included youth with a wide range of child characteristics, such as varying FSIQ and adaptive functioning scores, which is important given that many studies do not include individuals with an IQ below 70 or with an intellectual disability diagnosis.

Limitations

The present study also has limitations that impact the generalizability of the current results. Recognizably, it is not an experimental design with a control condition and, thus, no conclusive causal statements can be made regarding EIBI's effect on long-term mental health diagnoses or symptoms.

Further, limited information about the intervention was available, and the information that was available, included more crude measures. Specifically, there was no information available about the quality of the intervention, such as information about supervision and treatment integrity, which are known to impact child outcomes (Dixon et al., 2016; Långh et al., 2017; Långh et al., 2022; Reichow & Wolery, 2009). Further, limited information was available regarding the duration and intensity, including the number of hours they received EIBI per week and number of weeks per year they received EIBI. Therefore, there may be some concerns regarding the accuracy of the intervention experience, such as whether the intervention was actually EIBI. Additional information on the quality, duration, and intensity would be helpful in exploring how these factors impact mental health outcomes. Moreover, given that there was no information collected pre-EIBI, we are unable to explore pre-post changes or the effectiveness of EIBI in terms of mental health and autism severity.

In addition, only a subset of families who participated in the time 1 study continued to participate in the time 2 study. There is a possibility that there is a difference between those who participated in the time 2 study and those who did not, potentially including a difference in mental health status and autism severity. However, without information on who received EIBI (which was collected retrospectively at time 2), we are unable to explore if such a difference is present to determine if the generalizability of the study is impacted due to this.

Finally, although the use of parent-report measures can be very helpful in the collection of information, regarding individuals with intellectual disability in particular, it would be beneficial to have included multiple informants, including the youth themselves (whenever possible), in addition to more objective measures, such as observational methods, rather than just parent-report measures.

Future Research and Conclusion

The present paper demonstrates the need for additional research on the mental health and wellbeing of autistic youth who previously received EIBI. Our results suggest that there is a lot of variability in the outcomes for autistic youth who previously received EIBI, which is consistent with previous research. In general, autistic youth who received EIBI experience *higher* scores on a mental health symptom measure than the normative sample, although it appears they experience *lower* scores than the autistic population. Further, group means and most participants' mental health symptom scores were not in the clinical range indicating that youth who previously received EIBI are doing as well, if not better, than people on the spectrum in general. Additional research is needed to better understand the mental health and wellbeing of autistic youth who received EIBI. It would be helpful to explore the mental health of autistic youth using a variety of data collection methods and informants, including self-report and clinical interviewing. Further, it would be helpful to explore the difference in mental health and autism severity outcomes for autistic youth who received EIBI with similar autistic youth who did not, to gain a better estimate of the role of EIBI in relation to mental health in particular. It would also be helpful to include pre-intervention measures of mental health and autism severity to look at the trajectory of these factors pre- and post-intervention to explore whether EIBI is helpful in

supporting autistic youths' mental health, and if so, exploring specific areas of mental health (e.g., internalizing, externalizing) to determine if and where additional support is needed.

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Table 1

Sample Characteristics

	N	*M*	*SD*	*Min*	*Max*
Age (time 1, years)	42	8.83	3.53	4.00	16.92
Age (time 2, years)	42	14.22	3.80	9.08	23.83
Follow-up length (years)	42	5.39	0.97	3.92	7.42
Age received EIBI (onset, years)	42	3.14	0.95	2.00	5.00
Duration of EIBI (weeks)	42	99.81	49.59	42.00	200.00
Total hours of EIBI (hours x weeks)	42	7536.93	7804.81	840.00	30000.00
Total time since end of EIBI (years)	42	9.10	3.46	4.08	17.83
FSIQ (standard score) at time 1	42	70.90	29.67	18.00	125.00
Vineland ABC (standard score) at time 1	42	68.62	14.47	27.0	101.0

Note. EIBI: Early Intensive Behavioral Intervention; FSIQ: Full Scale IQ; ABC: Adaptive Behavior Composite.

Table 1

Parent-Reported Mental Health Diagnoses at Follow-up

	N	Yes	No	Not Sure
Anxiety disorder	33	8 (24.2%)	25 (75.8%)	0 (0.0%)
Depressive disorder	33	1 (3.0%)	31 (93.9%)	1 (3.0%)
Obsessive compulsive disorder	33	5 (15.2%)	27 (81.8%)	1 (3.0%)
ADHD	33	8 (24.2%)	24 (72.7%)	1 (3.0%)
More than one mental health diagnosis	33	6 (18.2%)	26 (78.8%)	1 (3.0%)

Table 2

Mental Health Status as Measured by the ABCL and CBCL

	N	*M*	*SD*	Min	Max
ABCL and CBCL participants					
Total problems	33	57.79	9.09	34	74
Internalizing	33	56.24	10.24	33	75
Externalizing	33	50.09	8.86	33	68
CBCL participants					
Affective problems (DSM-oriented scale)	30	58.33	7.42	50	75
Anxiety problems (DSM-oriented scale)	30	56.77	7.59	50	76
Somatic problems (DSM-oriented scale)	30	54.93	6.14	50	70
Attention-deficit/hyperactivity (DSM-oriented scale)	30	61.23	7.44	50	77
Opposition defiant problems (DSM-oriented scale)	30	53.60	4.91	50	69
Conduct problems (DSM-oriented scale)	30	54.07	5.34	50	65
Anxious/depressed (Syndrome scale)	30	57.27	9.78	50	87
Withdrawn/depressed (Syndrome scale)	30	61.70	7.72	50	82
Somatic complaints (Syndrome scale)	30	55.03	6.10	50	72
Social problems (Syndrome scale)	30	60.87	7.25	50	79
Thought problems (Syndrome scale)	30	66.30	8.63	50	79
Attention problems (Syndrome scale)	30	65.93	9.52	51	87
Rule-breaking behaviour (Syndrome scale)	30	52.63	3.86	50	64
Aggressive behaviour (Syndrome scale)	30	55.27	6.96	50	73

ABCL participants					
Depressive problems (DSM-oriented scale)	3	51.33	2.31	50	54
Anxiety problems (DSM-oriented scale)	3	50.00	0.00	50	50
Somatic problems (DSM-oriented scale)	3	51.33	2.309	50	54
Attention-deficit/hyperactivity (DSM-oriented scale)	3	52.00	2.65	50	55
Avoidant personality problems (DSM-oriented scale)	3	60.33	2.89	57	62
Antisocial personality problems (DSM-oriented scale)	3	50.67	1.16	50	52
Anxious/depressed (Syndrome scale)	3	50.67	1.16	50	52
Withdrawn/depressed (Syndrome scale)	3	59.67	4.04	56	64
Somatic complaints (Syndrome scale)	3	51.67	2.89	50	55
Thought problems (Syndrome scale)	3	56.00	8.50	50	66
Attention problems (Syndrome scale)	3	50.67	5.29	50	60
Rule-breaking behaviour (Syndrome scale)	3	53.00	3.00	50	51
Aggressive behaviour (Syndrome scale)	3	50.67	0.58	50	56
Intrusive (Syndrome scale)	3	50.33	0.58	50	51

Table 3

Categorization of ABCL and CBCL Scores

	N	Normal	Borderline	Clinical
ABCL and CBCL participants				
Total problems	33	20 (60.6%)	5 (15.2%)	8 (24.2%)
Internalizing	33	22 (66.7%)	2 (6.1%)	9 (27.3%)
Externalizing	33	26 (78.8%)	5 (15.2%)	2 (6.1%)
CBCL participants				
Affective problems (DSM-oriented scale)	30	22 (73.3%)	5 (16.7%)	3 (10.0%)
Anxiety problems (DSM-oriented scale)	30	23 (76.7%)	4 (13.3%)	3 (10.0%)
Somatic problems (DSM-oriented scale)	30	27 (90.0%)	1(3.3%)	2 (6.7%)
Attention-deficit/hyperactivity (DSM-oriented scale)	30	18 (60.0%)	8(26.7%)	4 (13.3%)
Opposition defiant problems (DSM-oriented scale)	30	28 (93.3%)	2(6.7%)	0 (0.0%)
Conduct problems (DSM-oriented scale)	30	28 (93.3%)	2 (6.7%)	0 (0.0%)
Anxious/depressed (Syndrome scale)	30	25 (83.33%)	2 (6.7%)	3 (10.0%)
Withdrawn/depressed (Syndrome scale)	30	19 (63.33%)	7 (23.3%)	4 (13.3%)
Somatic complaints (Syndrome scale)	30	27 (90.0%)	2 (6.7%)	1 (3.3%)
Social problems (Syndrome scale)	30	20 (66.7%)	7 (23.3%)	3 (10.0%)
Thought problems (Syndrome scale)	30	10 (33.3%)	7 (23.3%)	13 (43.3%)
Attention problems (Syndrome scale)	30	16 (53.3%)	6 (20.0%)	8 (26.7%)
Rule-breaking behaviour (Syndrome scale)	30	30 (100.0%)	0 (0.0%)	0 (0.0%)
Aggressive behaviour (Syndrome scale)	30	26 (86.7%)	3 (10.0%)	1 (3.3%)

ABCL participants				
Depressive problems (DSM-oriented scale)	3	3 (100.0%)	0 (0.0%)	0 (0.0%)
Anxiety problems (DSM-oriented scale)	3	3 (100.0%)	0 (0.0%)	0 (0.0%)
Somatic problems (DSM-oriented scale)	3	3 (100.0%)	0 (0.0%)	0 (0.0%)
Attention-deficit/hyperactivity (DSM-oriented scale)	3	3 (100.0%)	0 (0.0%)	0 (0.0%)
Avoidant personality problems (DSM-oriented scale)	3	3 (100.0%)	0 (0.0%)	0 (0.0%)
Antisocial personality problems (DSM-oriented scale)	3	3 (100.0%)	0 (0.0%)	0 (0.0%)
Anxious/depressed (Syndrome scale)	3	3 (100.0%)	0 (0.0%)	0 (0.0%)
Withdrawn/depressed (Syndrome scale)	3	3 (100.0%)	0 (0.0%)	0 (0.0%)
Somatic complaints (Syndrome scale)	3	3 (100.0%)	0 (0.0%)	0 (0.0%)
Thought problems (Syndrome scale)	3	2 (66.7%)	1 (33.3%)	0 (0.0%)
Attention problems (Syndrome scale)	3	3 (100.0%)	0 (0.0%)	0 (0.0%)
Rule-breaking behaviour (Syndrome scale)	3	3 (100.0%)	0 (0.0%)	0 (0.0%)
Aggressive behaviour (Syndrome scale)	3	3 (100.0%)	0 (0.0%)	0 (0.0%)
Intrusive (Syndrome scale)	3	3 (100.0%)	0 (0.0%)	0 (0.0%)

Table 4

Autism Symptom Severity Scores as Measured using the SRS-2

	N	*M*	*SD*	Min	Max
Total	36	74.28	12.29	43.00	90.00
Social awareness	36	71.08	13.51	37.00	103.00
Social cognition	36	70.28	12.95	41.00	92.00
Social communication	36	74.58	13.70	38.00	102.00
Social motivation	36	68.61	12.70	48.00	97.00
Restricted interests and repetitive behaviours	36	74.78	13.48	44.00	99.00

Table 5

Categorization of SRS-2 Scores

	N	Typical	Mild	Moderate	Severe
Total	36	4 (11.1%)	3 (8.3%)	12 (33.3%)	17 (47.2%)
Social awareness	36	5 (13.9%)	7 (19.4%)	10 (27.8%)	14 (38.9%)
Social cognition	36	8 (22.2%)	8 (22.2%)	6 (16.6%)	14 (38.9%)
Social communication	36	4 (11.1%)	4 (11.1%)	11 (30.6%)	17 (47.2%)
Social motivation	36	7 (19.4%)	10 (27.8%)	10 (27.8%)	9 (25.0%)
Restricted interests and repetitive behaviours	36	4 (11.1%)	4 (11.1%)	11 (30.6%)	17 (47.2%)

Table 6

Education at Follow-up (n=32)

	N (%)
Private school	8 (25.8%)
Special education teaching	6 (19.4%)
General education teaching	1 (3.2%)
Combination of general and special education teaching	1 (3.2%)
Public School	20 (64.5%)
Special education teaching	5 (16.1%)
General education teaching	6 (19. 4%)
Combination of general and special education teaching	9 (29.0%)
Other (e.g., home schooled)	3 (9.7%)
Special education teaching	2 (6.4%)
General education teaching	1 (3.2%)
Combination of general and special education teaching	0 (0.0%)

Table 7

Comparing EIBI Sample to Normative Sample using the CBCL

	N	*M(SD)*	*t*	*df*	*p*	*Hedge's g*
ABCL and CBCL participants						
Total problems	33	57.79(9.09)	4.918	32	<.001	0.836
Internalizing	33	56.24(10.24)	3.502	32	.001	0.595
Externalizing	33	50.09(8.86)	0.059	32	.477	0.010
DSM-oriented scales for CBCL participants						
Affective problems	30	58.33(7.42)	6.151	29	<.001	1.094
Anxiety problems	30	56.77(7.59)	4.885	29	<.001	0.869
Somatic problems	30	54.93(6.14)	4.404	29	<.001	0.783
Attention-deficit/hyperactivity	30	61.23(7.44)	8.270	29	<.001	1.470
Opposition defiant problems	30	53.60(4.91)	4.016	29	<.001	0.714
Conduct problems	30	54.07(5.34)	4.174	29	<.001	0.742
Syndrome scales for CBCL participants						
Anxious/depressed	30	57.27(9.78)	4.068	29	<.001	0.723
Withdrawn/depressed	30	61.70(7.72)	8.306	29	<.001	1.477
Somatic complaints	30	55.03(6.10)	4.520	29	<.001	0.804
Social problems	30	60.87(7.25)	8.212	29	<.001	1.460
Thought problems	30	66.30(8.63)	10.349	29	<.001	1.840
Attention problems	30	65.93(9.52)	9.164	29	<.001	1.629
Rule-breaking behaviour	30	52.63(3.86)	3.733	29	<.001	0.664
Aggressive behaviour	30	55.27(6.96)	4.146	29	<.001	0.737

Table 8

Chi-Squared Analyses to Compare Percentage of Individuals in the Clinical Range

		EIBI (%)	Referred (%)	χ^2	*p*
Total problems	Clinical	43	75	21.1658	< .001
	Typical	57	25		
Internalizing	Clinical	37	65	15.686	< .001
	Typical	63	35		
Externalizing	Clinical	23	73	50.080	< .001
	Typical	77	27		
Affective problems	Clinical	27	54	15.126	< .001
	Typical	73	46		
Anxiety problems	Clinical	23	39	5.984	< .001
	Typical	77	61		
Somatic problems	Clinical	10	24	6.945	< .001
	Typical	90	76		
Attention-deficit/	Clinical	40	47	0.997	.318
hyperactivity	Typical	60	53		
Opposition defiant problems	Clinical	7	50	45.369	< .001
	Typical	93	50		
Conduct problems	Clinical	7	57	57.445	< .001
	Typical	93	43		

Anxious/depressed	Clinical	10	45	30.721	< .001
	Typical	90	55		
Withdrawn/depressed	Clinical	37	45	1.323	.250
	Typical	63	55		
Somatic complaints	Clinical	10	27	9.584	< .001
	Typical	90	73		
Social problems	Clinical	27	46	7.788	< .001
	Typical	73	54		
Thought problems	Clinical	67	44	10.710	< .001
	Typical	33	56		
Attention problems	Clinical	47	48	0.015	.904
	Typical	53	52		
Rule-breaking behaviour	Clinical	0 (1)*	45	54.658	< .001
	Typical	100	55		
Aggressive behaviour	Clinical	7	58	59.282	< .001
	Typical	93	42		

Note. *Rule breaking behaviour chi-squared analysis was run with 1 in the clinical group and 100 in the typical group in order to get an estimate of the difference.

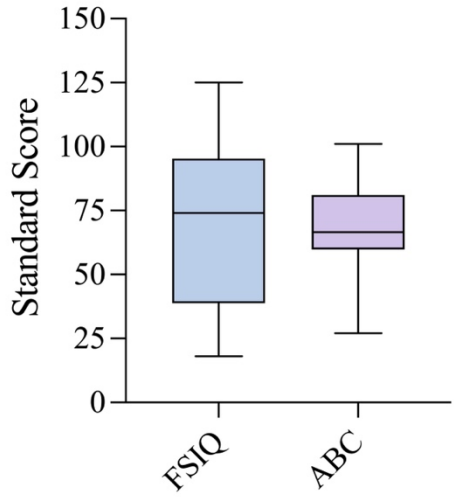
Table 9

Comparing EIBI Sample to Normative Sample using the SRS-2

	N	*M(SD)*	*t*	*df*	*p*	*Hedge's g*
Total	36	74.28(12.29)	11.852	35	<.001	1.933
Social awareness	36	71.08(13.51)	9.363	35	<.001	1.527
Social cognition	36	70.28(12.95)	9.397	35	<.001	1.532
Social communication	36	74.58(13.70)	10.763	35	<.001	1.755
Social motivation	36	74.78(13.48)	11.032	35	<.001	1.799
Restricted interests and repetitive behaviours	36	68.61(12.70)	8.792	35	<.001	1.434

Figure 1

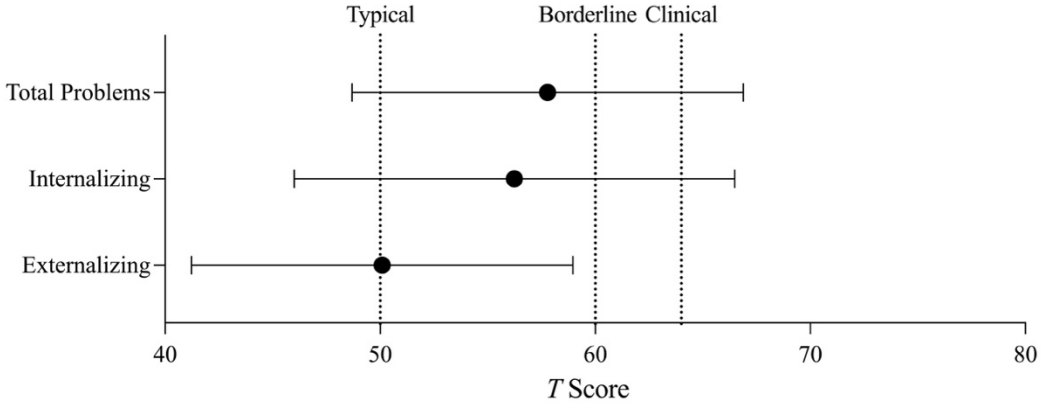
Boxplot of Cognitive and Adaptive Functioning



Note. FSIQ: Full Scale IQ; ABC: Adaptive Behavior Composite.

Figure 2

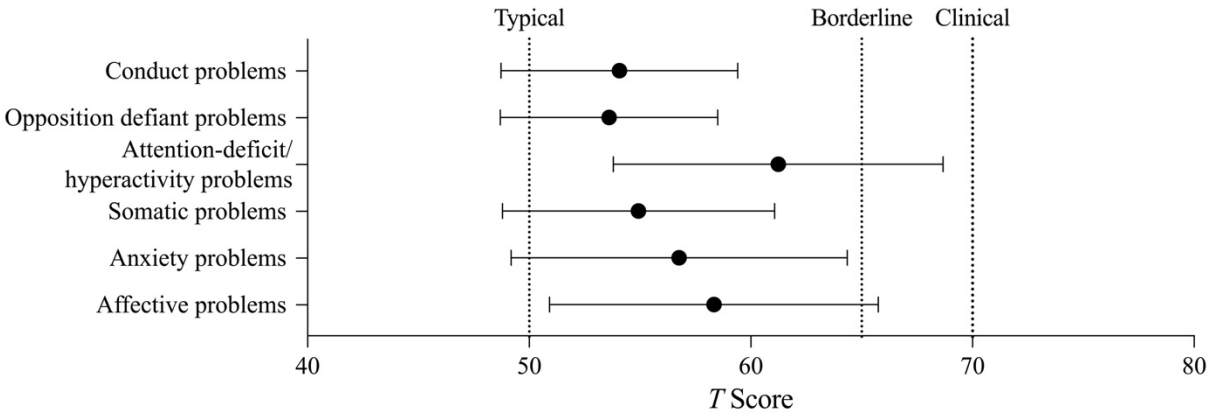
Group Means of CBCL Broadband Scores with Clinical Cut-offs



Note. Circles denote the group mean and the error bars represent the standard deviation.

Figure 2

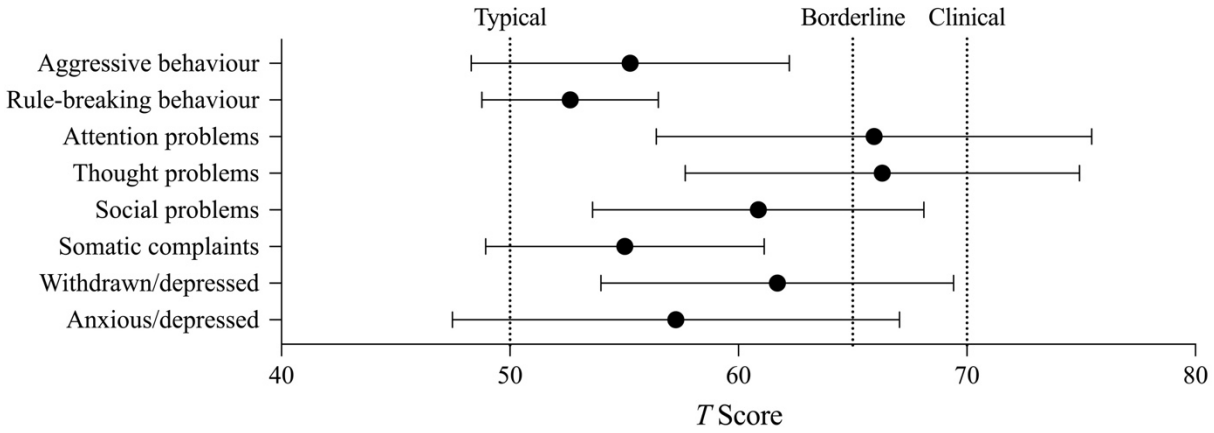
Group Means of CBCL DSM-Oriented Scores with Clinical Cut-offs



Note. Circles denote the group mean and the error bars represent the standard deviation.

Figure 4

Group Means of CBCL Syndrome Scores with Clinical Cut-offs



Note. Circles denote the group mean and the error bars represent the standard deviation.

Figure 5

Individual CBCL Broadband Scores

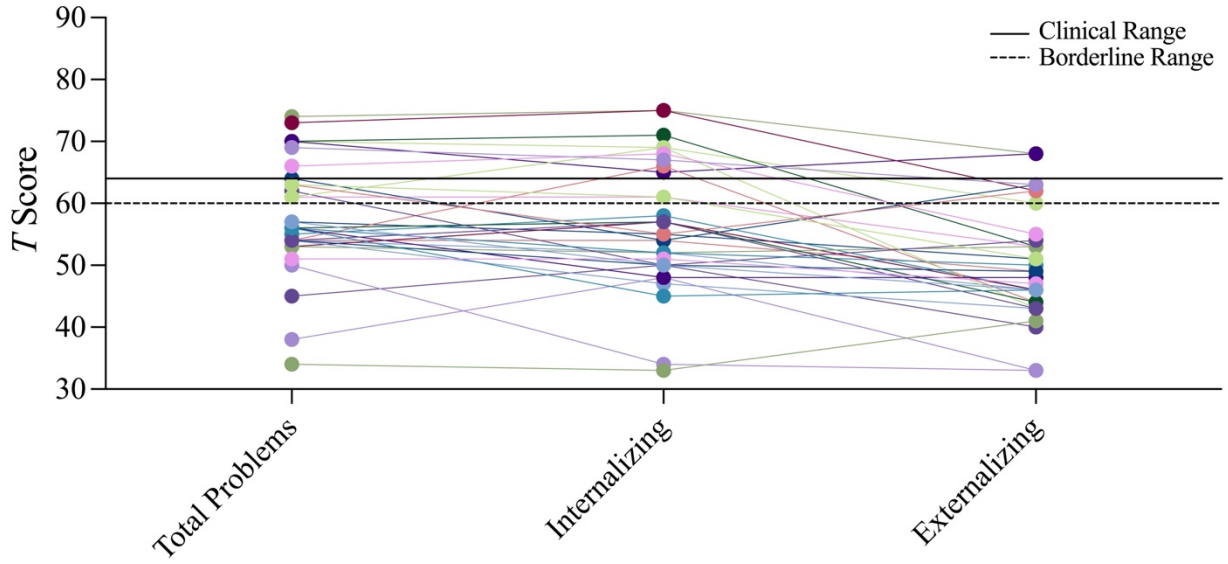


Figure 6

Individual CBCL DSM-Oriented Scores

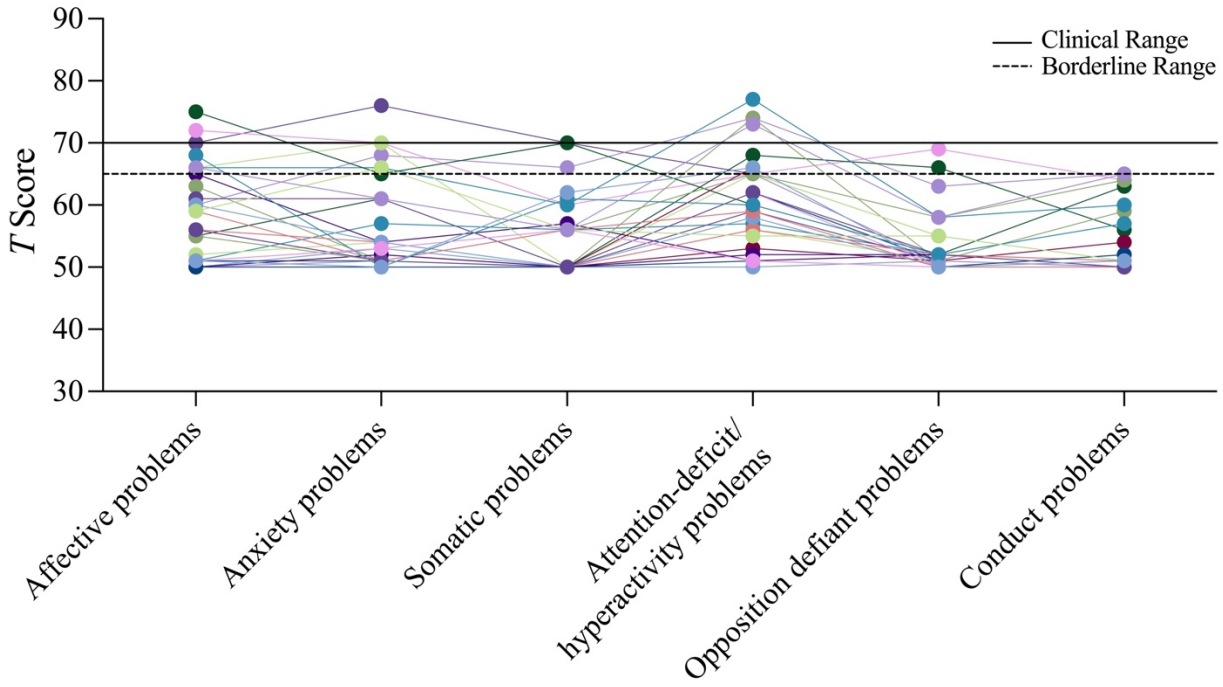


Figure 3

Individual CBCL Syndrome Scores

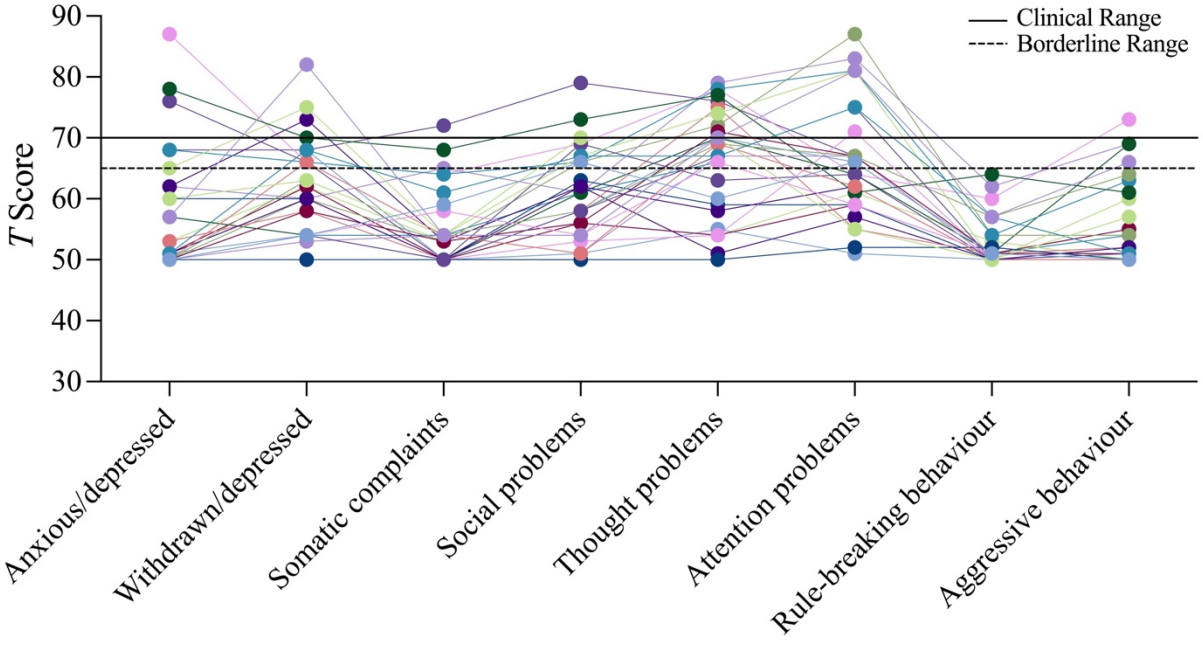


Figure 8

Categorization of ABCL and CBCL Broadband Scores

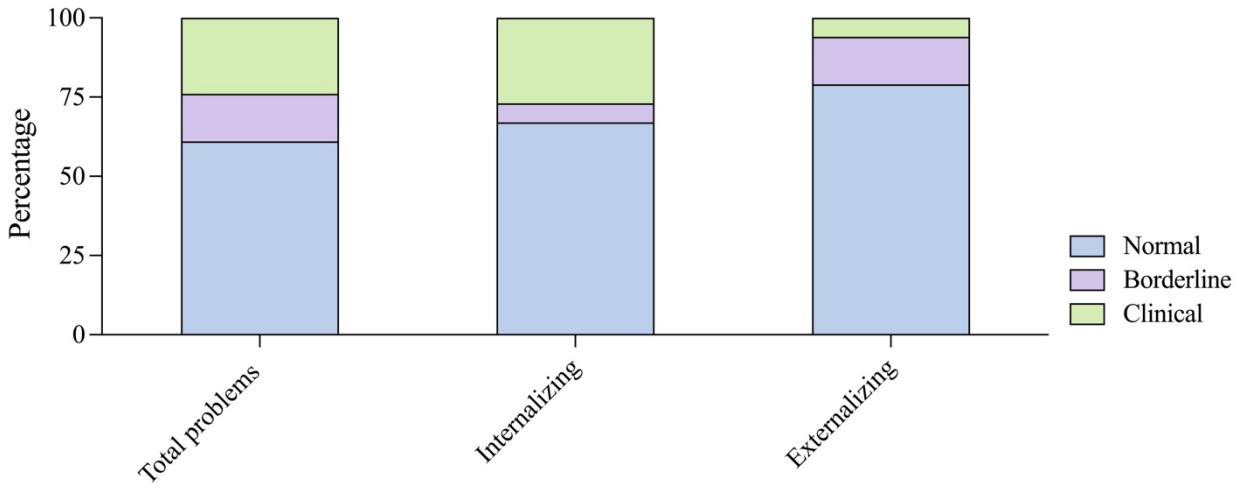


Figure 4

Categorization of CBCL DSM-Oriented Scores

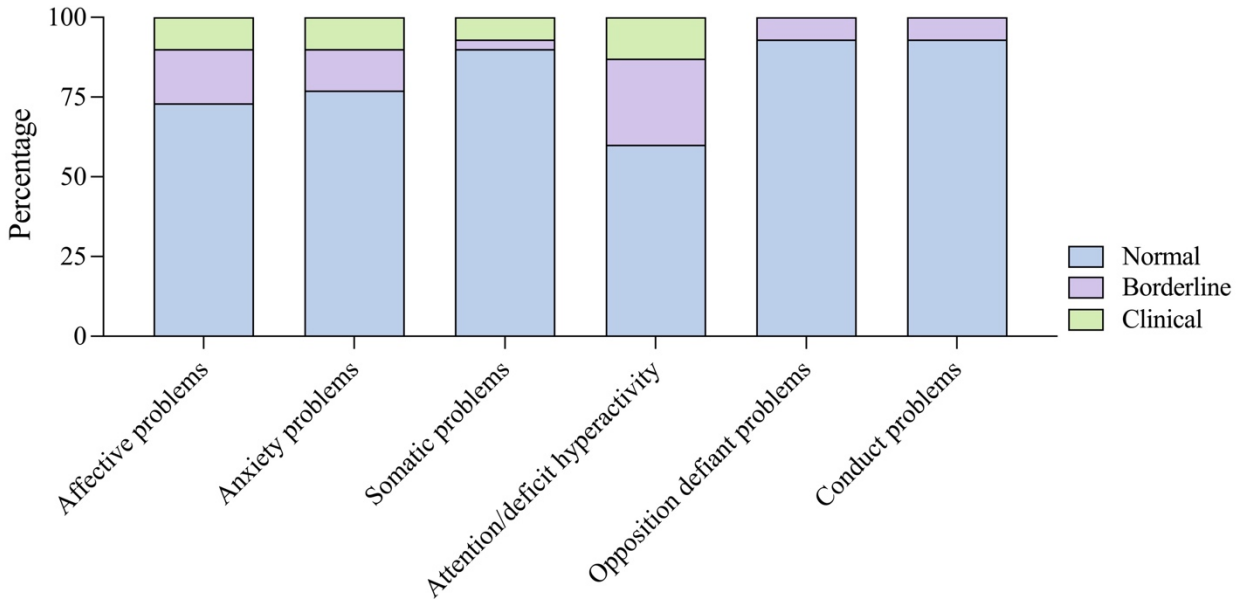


Figure 5

Categorization of CBCL Syndrome Scores

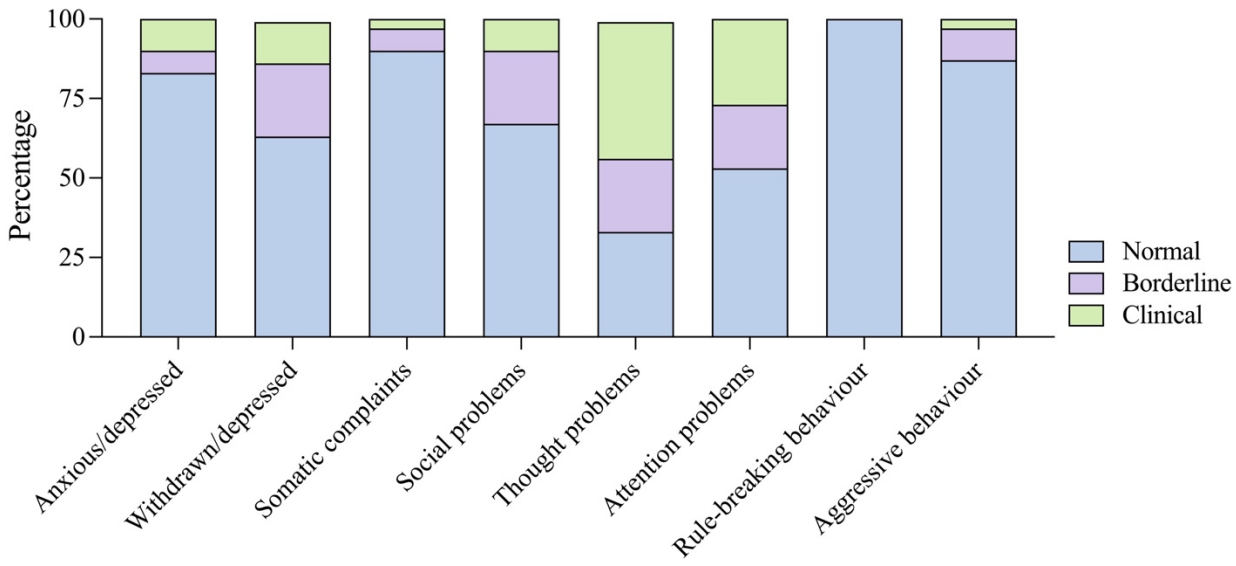
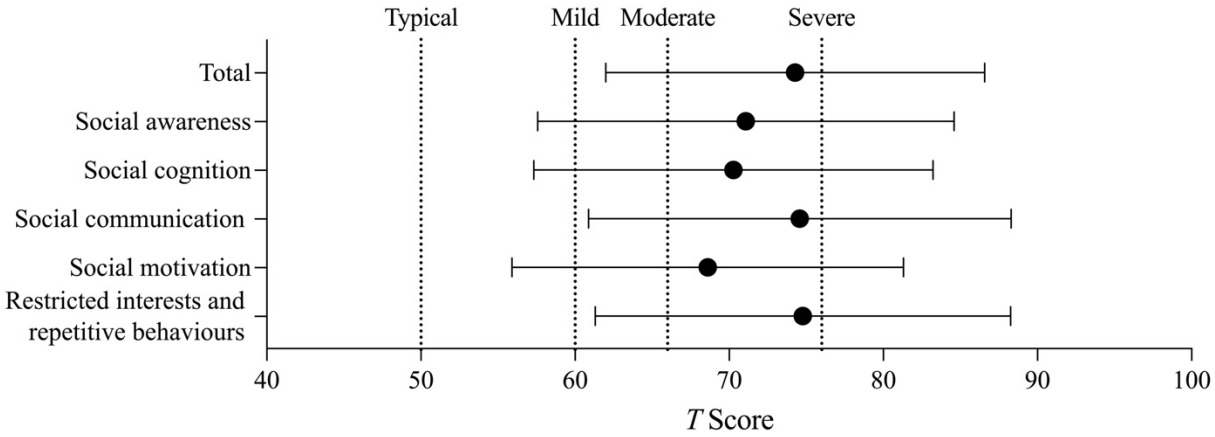


Figure 6

Group Means of SRS-2 Total and Subscales with Clinical Cut-offs



Note. Circles denote the group mean and the error bars represent the standard deviation.

Figure 7

Individual SRS-2 Total and Subscale Scores

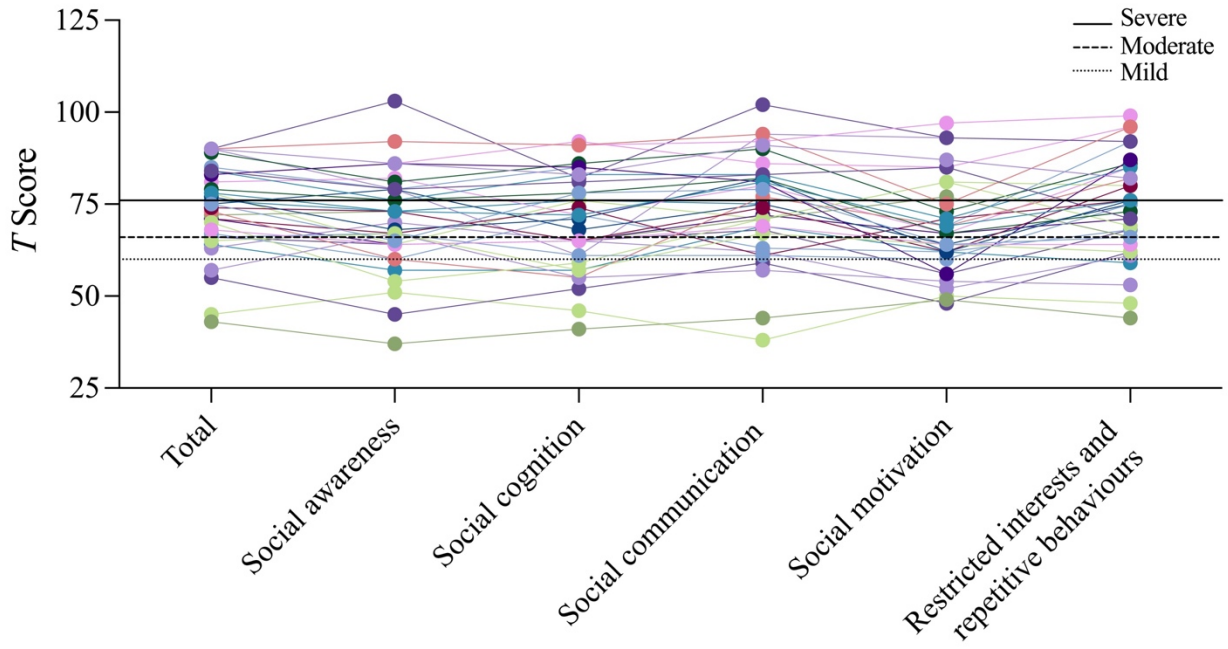


Figure 8

Categorization of SRS-2 Scores

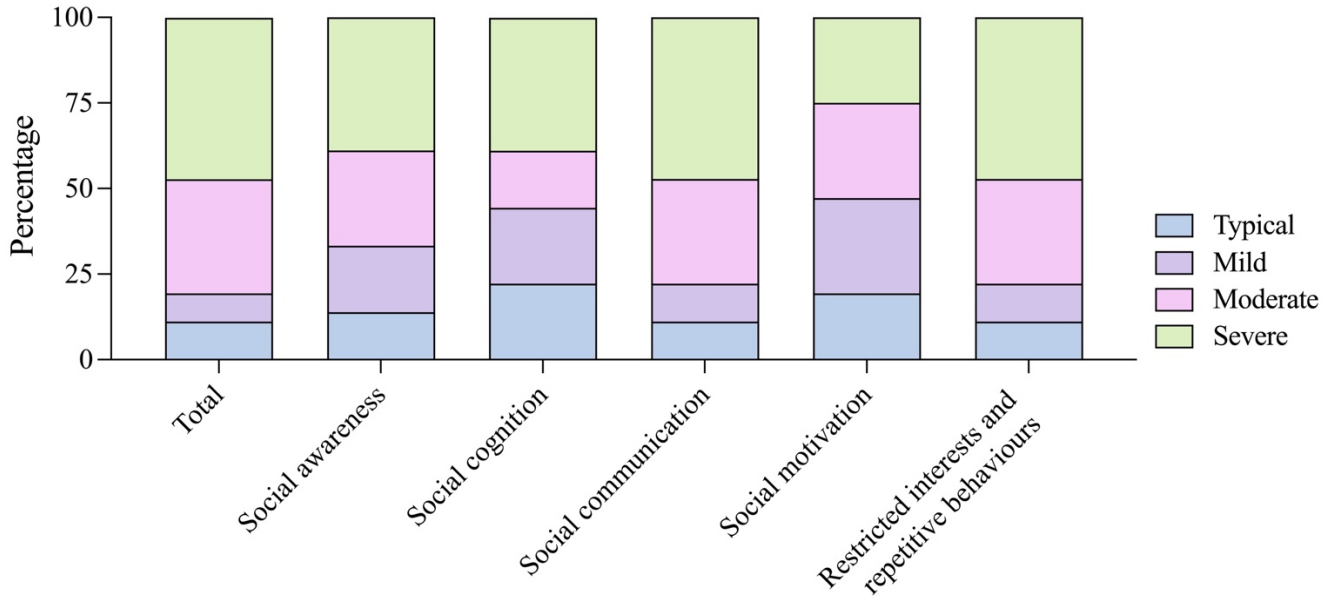
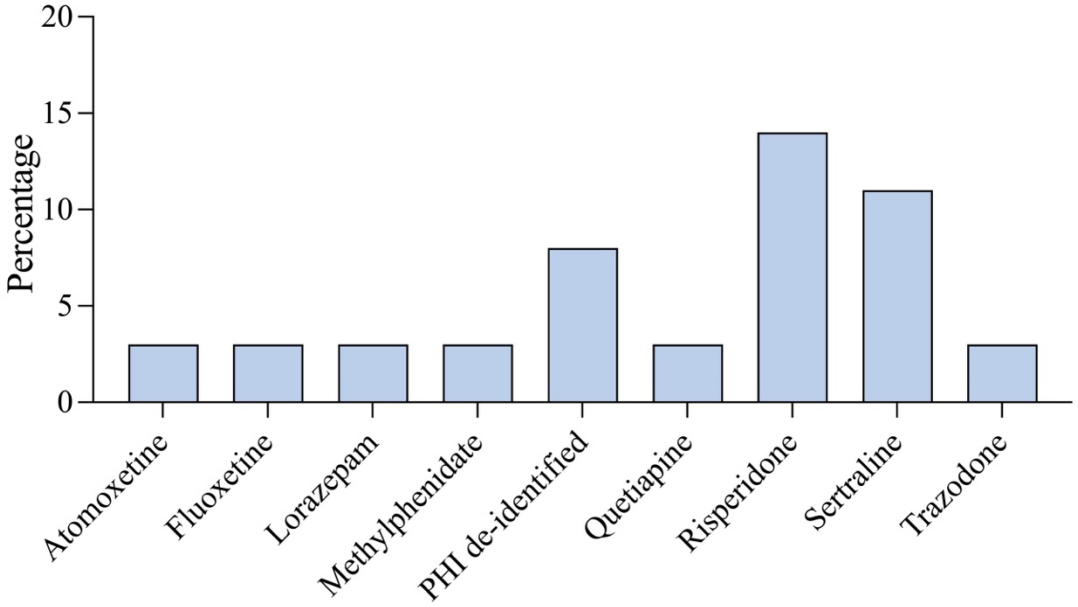


Figure 9

Percentage of Medication Use by Type



Note. PHI: Personal Health Information.

Figure 10

Percentage of Participants Who Received Each Type of Education

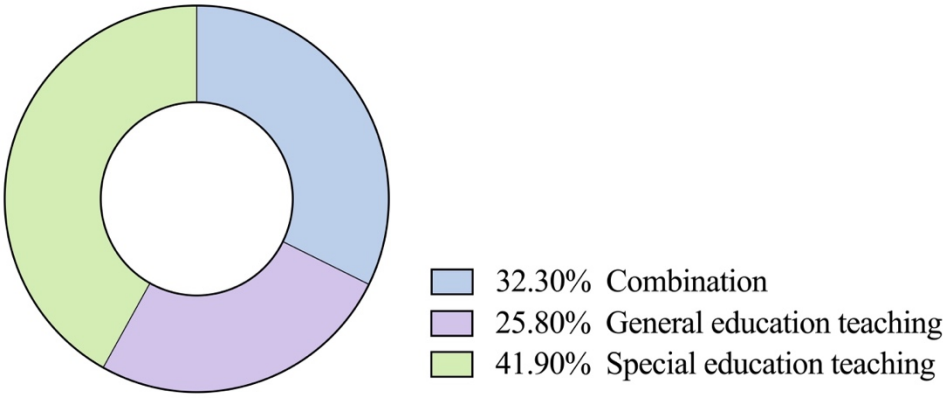
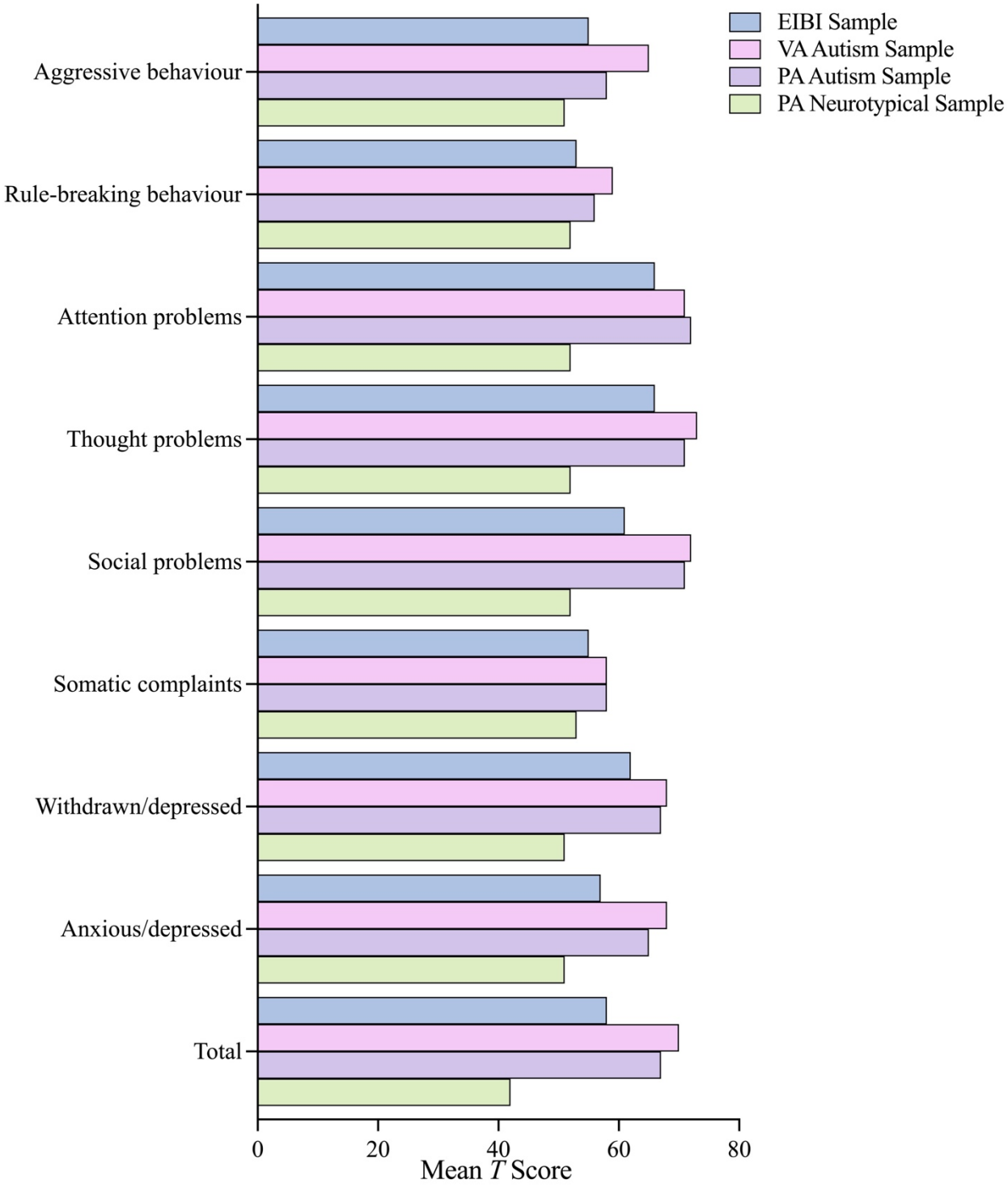


Figure 11

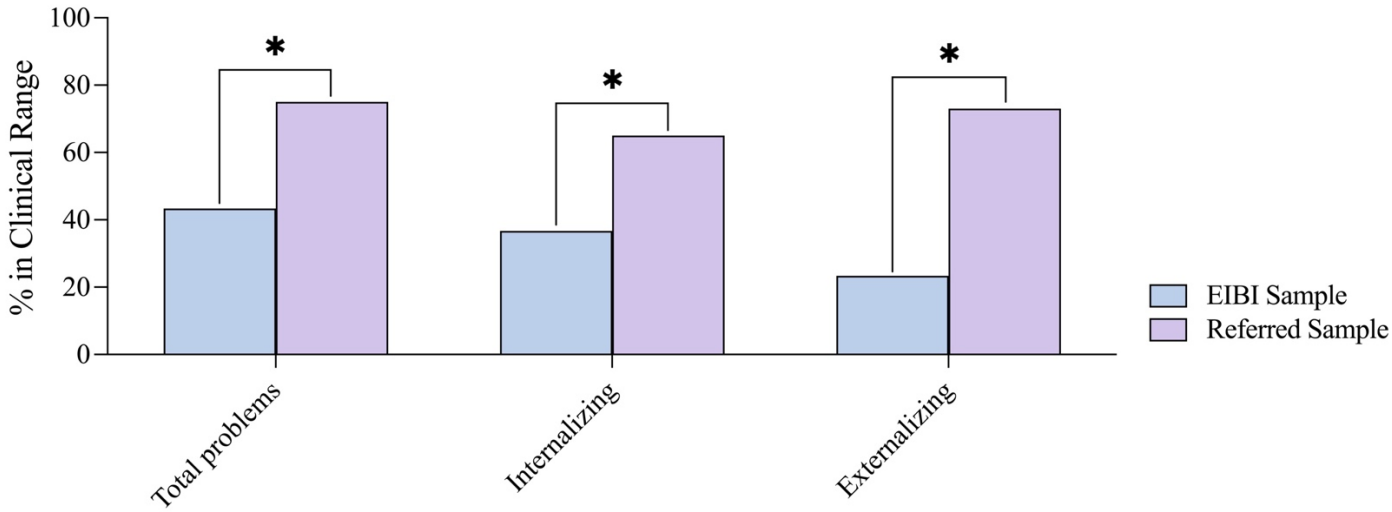
Comparing the Group Means from the EIBI Sample with Mazefsky et al. (2011)'s Samples



Note. PA: Pennsylvania; VA: Virginia.

Figure 12

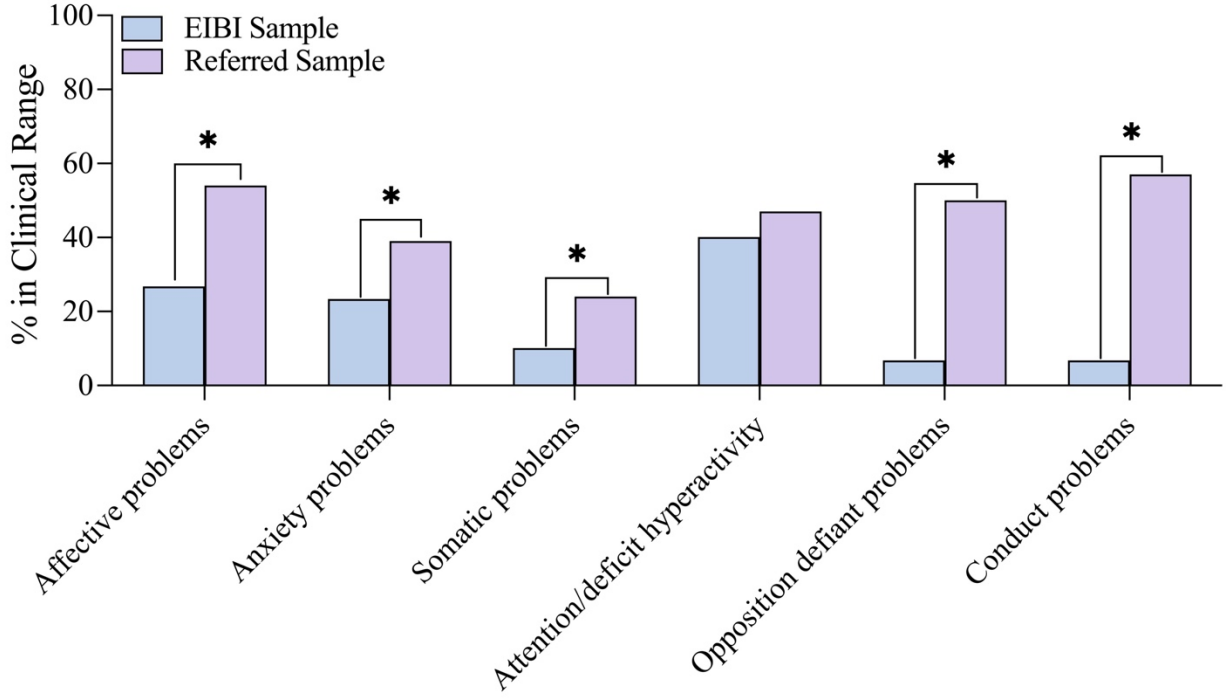
Comparison of EIBI Sample to Referred Sample on Broadband Scores



Note. $^{*}p < .05$

Figure 18

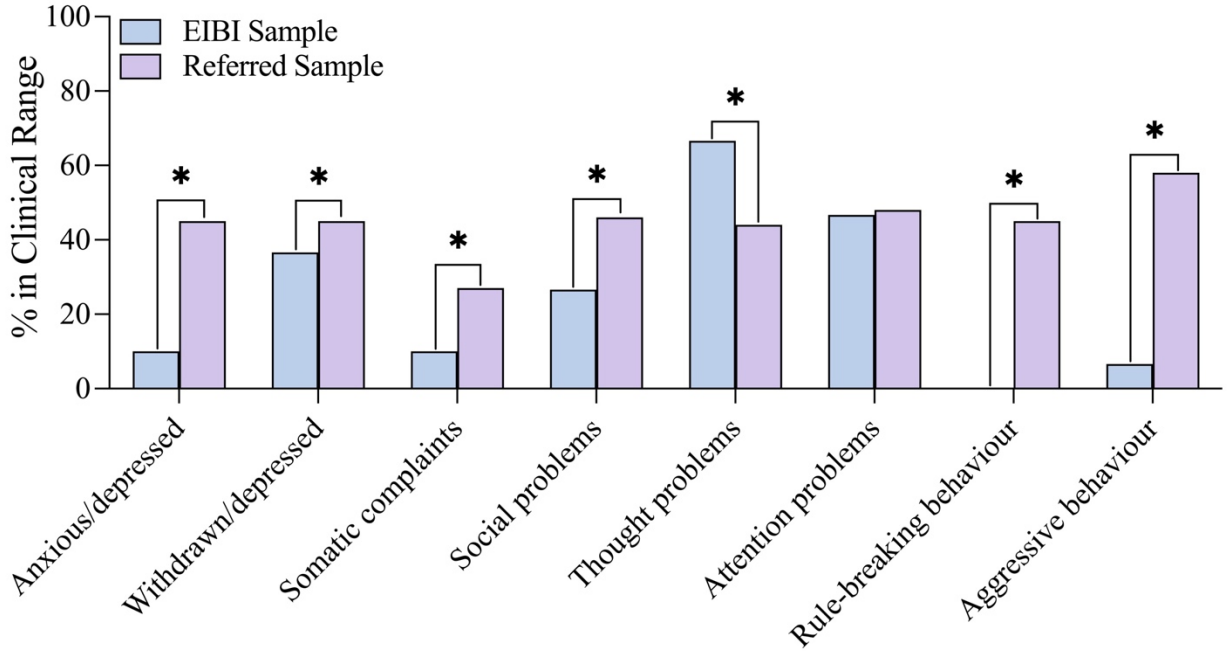
Comparison of EIBI Sample to Referred Sample on CBCL DSM-Oriented Scales



Note. $^{*}p < .05$

Figure 13

Comparison of EIBI Sample to Referred Sample on CBCL Syndrome Scales



Note. $^{*}p < .05$

Figure 14

Comparison of EIBI Sample to Mazefsky et al. (2011)'s Samples on Percent in the Clinical Ranges for CBCL Total and Syndrome Scales

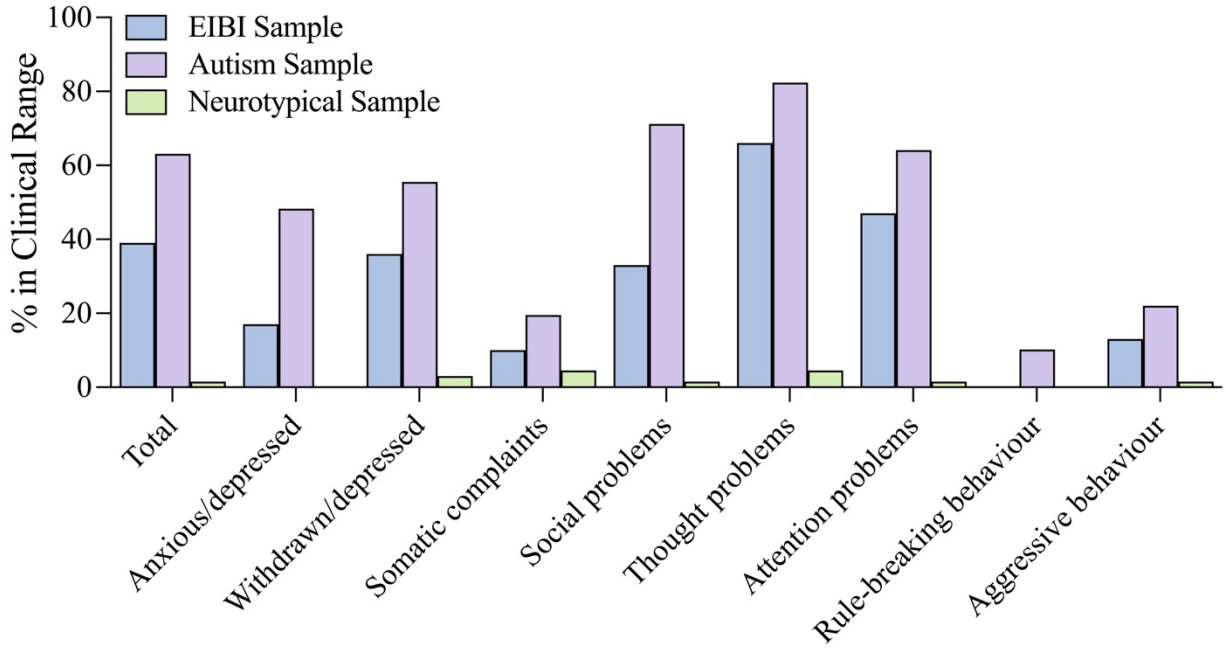


Figure 15

Comparison of EIBI Sample to Normative Sex-Based Samples on SRS-2 Total and Subscales

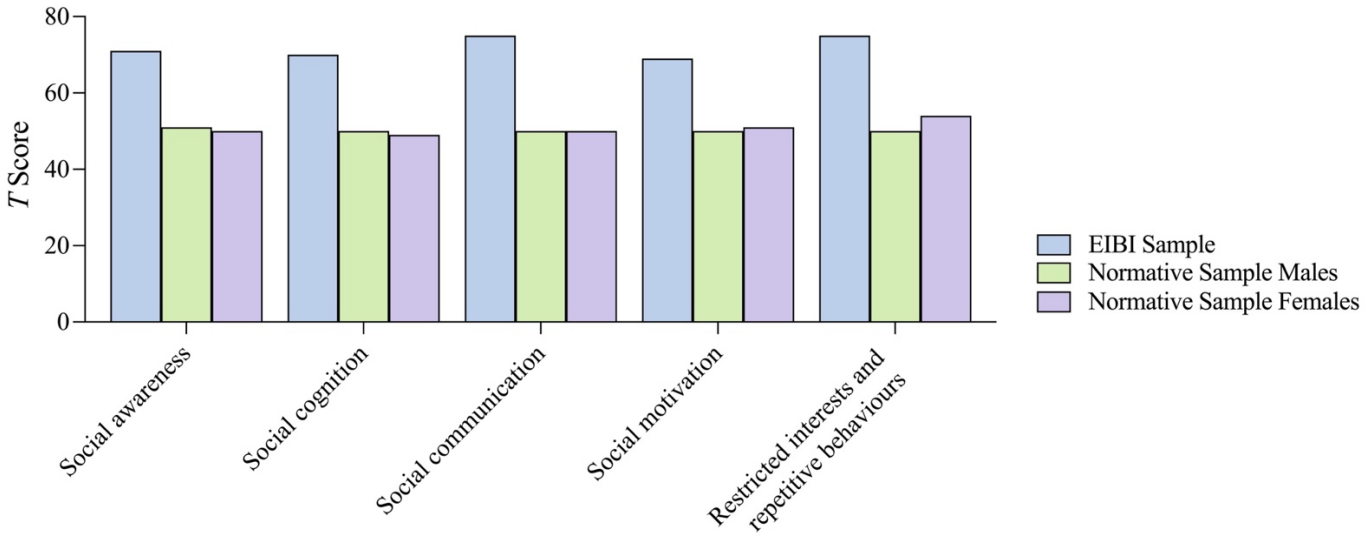


Figure 16

Comparison of SRS-2 Total Scores for EIBI Sample and Study Samples

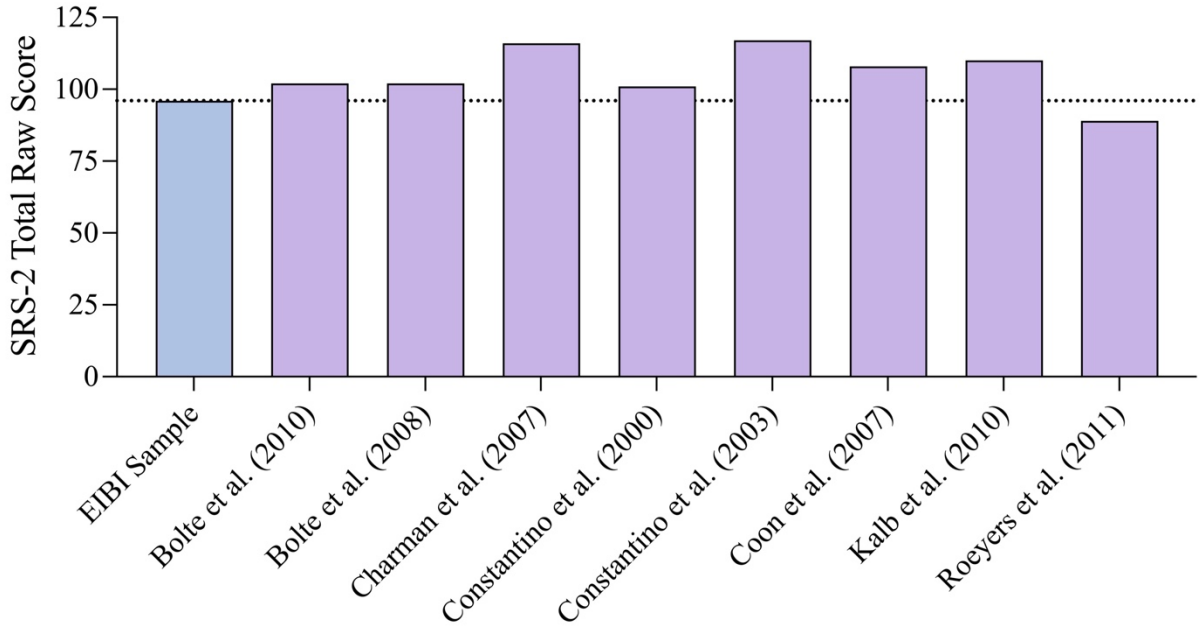


Figure 17

Comparison of EIBI Sample and Kalb et al. (2011)'s Sample on SRS-2 Subscales