#### **BRIEF REPORT**



# The Association Between Autism Symptomatology and Adaptive Functioning Over Six Months: Findings from the Pilot Phase of the PARC Study

Tamar David Cohen<sup>1</sup> · Judah Koller<sup>1</sup> · Eric Duku<sup>2</sup> · Anna Kata<sup>2</sup> · Colleen Anderson<sup>3</sup> · Teresa Bennett<sup>2</sup> · Amber Cauwenbergs<sup>4</sup> · Kathleen Dekker<sup>4</sup> · Briano DiRezze<sup>5</sup> · Irene Drmic<sup>4</sup> · Judy Eerkes<sup>4</sup> · Stephen J. Gentles<sup>2</sup> · Kathy Georgiades<sup>2</sup> · Lorraine Hoult<sup>4</sup> · Olaf Kraus De Camargo<sup>6,8</sup> · Bill Mahoney<sup>6</sup> · Ronit Mesterman<sup>6</sup> · Olivia Ng<sup>7</sup> · Sue Robertson<sup>7</sup> · Caroline Roncadin<sup>4</sup> · Stelios Georgiades<sup>2</sup>

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#### Abstract

**Purpose** In the context of developmental trajectories, the association between adaptive functioning and core autism symptomatology remains unclear. The current study examines the associations of adaptive behavior with autism symptom sub-domains and with different facets of symptom expression.

**Methods** Participants include 36 children with a recent diagnosis of autism (33 males; mean age = 56.4 months; SD=9 months). Families were recruited in the context of the Pediatric Autism Research Cohort (PARC) project. Parents filled out questionnaires at two time points, six months apart, regarding their child's autism symptoms and adaptive functioning. The longitudinal relationship between adaptive functioning and autism symptoms was investigated using Mixed Linear Model analyses: one assessing the relationship between general symptom levels and adaptive functioning, and another examining the associations between symptom *frequency* and *impact* with adaptive functioning. We conducted Pearson correlation tests at both time points to assess the associations between symptom sub-domains and adaptive functioning.

**Results** Findings showed that higher autism symptoms associated with lower adaptive behavior skills, and that this association remained stable over time. Autism *impact* scores did not significantly relate to adaptive skills, as opposed to *frequency* scores. Associations between adaptive functioning and autism symptom sub-domains strengthened over time.

**Conclusion** These findings suggest that adaptive functioning is associated with parent-report autism symptomatology, and that this association changes and, on average, becomes stronger over time. Findings may indicate that *frequency* and *impact* of symptoms have differential roles in the development of adaptive skills and are worthy of further exploration.

Keywords Autism · Adaptive Functioning · Developmental Trajectories · Early Development · Social Communication · Restricted and Repetitive Behavior

⊠ Tamar David Cohen Tamardavi@gmail.com

- <sup>1</sup> Hebrew University of Jerusalem, Seymour Fox School of Education, Jerusalem, Israel
- <sup>2</sup> Psychiatry and Behavioral Neurosciences, McMaster University, Hamilton, ON, Canada
- <sup>3</sup> McMaster Children's Hospital, Hamilton, ON, Canada
- <sup>4</sup> Autism Program, McMaster Children's Hospital, Hamilton, ON, Canada
- <sup>5</sup> School of Rehabilitation Science, McMaster University, Hamilton, ON, Canada
- <sup>6</sup> McMaster University, Pediatrics, Hamilton, ON, Canada
- <sup>7</sup> Developmental Pediatrics and Rehabilitation Program, McMaster Children's Hospital, Hamilton, ON, Canada
- <sup>8</sup> CanChild Centre for Childhood Disability Research, McMaster University, Hamilton, ON, Canada

Autism spectrum disorder (henceforth "autism"; Kenny et al., 2015) is a pervasive neurodevelopmental disorder characterized by impairment in social communication and interaction, and restricted and repetitive patterns of behavior, interests, or activities (RRBs; American Psychiatric Association (APA), 2013). There is vast heterogeneity within the autistic population, encompassing individuals who require from mild to substantial support as well as those with varying levels of language use, intellectual abilities, and co-occurring disorders (APA, 2013; Kim et al., 2016; Georgiades et al., 2017a). In addition, there are varied developmental trajectories of symptom severity and functioning levels. Understanding the nature of phenotypic heterogeneity in a developmental framework is essential in order to assess what interventions benefit which children when (Georgiades et al., 2017a).

Research on early developmental trajectories in autism has focused a great deal on the core symptoms, delineated above, showing that different groups of children display different levels of symptom severity, as well as varied patterns of change over time. While some groups' symptomatology improves over time, others display stable symptom expression or worsening over time (Georgiades et al., 2014; Lord et al., 2015; Szatmari et al., 2015; Kim et al., 2016). Moreover, some studies show that the composition of subgroups identified at one time point may not remain stable at a later time point, suggesting that individuals deviate from their original trajectory throughout their development (Georgiades et al., 2014). The variability in symptomatology has been shown to associate with age of diagnosis, wherein symptoms of children diagnosed earlier tend to improve over time (Szatmari et al., 2015).

Another essential factor to consider in the context of early development in autism is adaptive functioning, which refers to everyday skills including functional use of communication, social skills, daily living skills, and motor abilities (Sparrow et al., 2016). Adaptive functioning has a significant effect on both children's and adult's ability to function independently and lead a full and productive life, thus directly impacting individual and family well-being (Farley et al., 2009; Kuhlthau et al., 2010; Chiang & Wineman, 2014; Gardiner & Iarocci, 2015). In addition, better adaptive and intellectual abilities have been shown to facilitate improvement in therapy for children with autism (Kim et al., 2016). Research shows children with autism tend to have lower adaptive functioning skills than typically developing children and those with other developmental disorders (Alvares et al., 2020; Franchini et al., 2018).

As in symptom severity, adaptive functioning skills vary significantly between children and associate with different developmental trajectories (Franchini et al., 2018; Tillmann et al., 2019; Szatmari et al., 2015; Kim et al., 2016). Higher

levels of adaptive functioning have been associated with earlier language development and better intellectual abilities, although the latter findings are inconsistent (Szatmari et al., 2015; Chatham et al., 2018; Alvares et al., 2020). Lower levels of adaptive functioning were also found to be associated with disruptive behaviors (Franchini et al., 2018; Georgiades et al., 2014).

In the context of developmental trajectories, the association between adaptive functioning and autism symptomatology remains unclear. While these two constructs appear to be linked for some children, for others they seem to develop on independent trajectories. The way in which these variables are associated with each other appears to be influenced by additional clinical features, including intellectual abilities, language skills, and emotional and behavioral problems (Georgiades et al., 2014; Lord et al., 2015; Szatmari et al., 2015; Kim et al., 2016).

Findings are also inconclusive regarding the way in which adaptive functioning is associated with specific subdomains of autism symptoms (Franchini et al., 2018; Wolff et al., 2014). Studies indicate an association between the severity of social communication symptoms and impairments in adaptive functioning, especially in the socialization domain. These social and communication difficulties may affect children's ability to engage in natural learning opportunities, inhibiting their acquisition of adaptive skills (Franchini et al., 2018; Tillmann et al., 2019).

The relationship between adaptive functioning and RRBs is less established, with some studies indicating an association between the two (Troyb et al., 2016; Wolff et al., 2014; Gabriels et al., 2005) and others suggesting that RRBs are not a significant predictor of adaptive functioning (Tillmann et al., 2019). It seems that this association depends on age, with RRBs more closely linked to adaptive functioning at older ages. Moreover, certain aspects of RRBs were more closely related to adaptive functioning than others, namely stereotypical, compulsive, and restricted behaviors (Troyb et al., 2016; Wolff et al., 2014). It is noteworthy that some work points to the significance of other clinical features, such as intellectual abilities, as necessary for contextualizing the link between RRBs and adaptive functioning (Gabriels et al., 2005; Tillmann et al., 2019). Despite this, research indicates that RRBs may play a significant role in children's ability to learn (Kim et al., 2024). Conversely, the lack of appropriate adaptive skills may create difficulties in functional play and behavior, causing children to utilize RRBs to self-regulate or to fill the void in their behavioral repertoire (Wolff et al., 2014; Leekam et al., 2011).

When considering the association between symptom severity and adaptive functioning, it is important to take into account the different ways symptoms are measured. Previous research has shown that parent-report measures tend to be more highly correlated with adaptive functioning than clinical observation measures (Tomaszewski et al., 2020). Though lacking the purportedly objective perspective of clinical observation, parent-report measures give us access to the parents view of child symptomatology across settings. Kanne and colleagues (2014) suggest a new approach to parent-report symptom measurement, factoring in both the parent's perceived *frequency* of symptoms and their *impact* on the child's everyday functioning. The *frequency* sub-scale allows us to track short-term changes in the occurrence of symptoms, identify high-frequency symptoms, and detect incremental change in their presentation. The impact sub-scale is a measure of the functional impact of symptoms on everyday life, which can highlight the specific symptoms or sub-domains of symptoms that are interfering with the individual's functioning. These aspects of symptom expression serve as separate constructs, such that some symptoms can be frequent without causing an interference to everyday functioning, while others can be detrimental even when occurring infrequently. Using this approach may extend our understanding of the ways different facets of symptom expression relate to children's adaptive functioning.

The objective of the current study was to examine the relationship between adaptive functioning and autism symptomatology in young children with a recent diagnosis of autism, at a single time point and over a six-months period. Data was obtained from the pilot phase of the Pediatric Autism Research Cohort (PARC) project (Koziarz et al., 2021), an international multi-site study focused on identifying and understanding factors influencing developmental trajectories in children with autism (Kata et al., 2024). In this context, we sought to examine whether adaptive functioning is differentially associated with the two different symptom sub-domains within autism (i.e., social communication and RRBs) and with varying facets of symptom expression (i.e., *impact* and *frequency*).

Since previous research on the link between general symptom severity and adaptive functioning has yielded conflicting results, and because of the pilot nature of the data, our analysis of this relationship was exploratory. We expected this association to change over time but did not presuppose the direction of the change. In line with extant literature (e.g., Tillmann et al., 2019), we hypothesized that symptoms belonging to DSM-5's criteria A (i.e., social communication) would more strongly associated with adaptive functioning than those belonging to criteria B (i.e., RRBs). Since the *impact* sub-scale is thought to measure the functional effect of symptoms, we hypothesized that it would more strongly relate to adaptive functioning than the reported *frequency*. To the best of our knowledge, this is the first study to examine the relationship between adaptive functioning and symptomatology using this approach.

## Methods

#### **Participants and Procedure**

Participants include 36 children (34 males, mean age = 56.4 months, SD = 9 months). All children met the inclusion criteria of having a formal clinical autism diagnosis from the community (Kata et al., 2024) and being under the age of 6 years at enrollment.

Families were recruited from McMaster Children's Hospital in Ontario, Canada, in the context of the pilot phase of the Pediatric Autism Research Cohort (PARC) project. The study was approved by the Hamilton Integrated Research Ethics Board (ID: 2902), and written consent was obtained from the participating caretakers. Parents filled out questionnaires in 6-month intervals over 2 years, answering questions regarding their child's autism symptomatology and adaptive functioning. Research team members were available to provide support and clarify questions for participants should any arise. For this study, we utilized data from two consecutive time points that were six months apart. Given the modest sample size and the pilot nature of this study, we chose the pair of time points with the largest sample sizes for the relevant data.

#### Measures

**Socio-Demographic Questionnaire** This questionnaire collected information about the child's age and gender, and about the family's socio-cultural background, parental education, housing status, occupational status, income, and support and services received by the family (Georgiades et al., 2017a).

Vineland Adaptive Behavioral Scales Parent/Caregiver Domain-Level Form, 3rd ed. (VABS-3) The VABS-3 is a standardized questionnaire that consists of 180 items designed to assess children's adaptive behavior. The VABS contains a composite score, as well as scores in the domains of communication, socialization, daily living skills, and motor abilities (only until the age of 5). Scores on the VABS are standardized by age (M=100, SD=15), with higher scores indicating better adaptive functioning. The VABS-3 domains have excellent psychometric properties with a coefficient alpha for internal consistency ranging between 0.86 and 0.97 (Sparrow et al., 2016).

Autism Impact Measure (AIM) The AIM is a measure of *frequency* and *impact* of autism symptoms that is sensitive to short-term change. The AIM consists of 41 items, each rated on a 5-point Likert scale ranging from 1 (never) to 5 (always). The AIM assesses the *frequency* of symptoms

(*frequency* sub-scale, ranging between 41 and 205) and their effect on child's everyday functioning (*impact* subscale, ranging between 41 and 205), as well as the combination of the two (total score, ranging between 82 and 410), with higher scores indicating higher levels of severity. In addition, there are five subscales comprising symptom sub-groups - communication, social reciprocity, peer interaction, repetitive behavior, and atypical behavior. The AIM was found to be a reliable and valid measure for shortterm change in autism symptomatology (Kanne et al., 2014; Mazurek et al., 2020; Mazurek et al., 2020b).

#### **Data Analysis**

To investigate the longitudinal relationship between adaptive functioning and autism symptoms, Mixed Linear Model (MLM) analyses were conducted. The first model used the

 Table 1
 Baseline demographics and clinical characteristics of the children in the study

Baseline characteristic	п	%
Gender		
Male	33	91.7
Female	3	8.3
Parent Yearly Income in CAD		
Up to 20,000	5	13.9
20,001-70,000	13	36.1
Over 70,001	16	44.4
N/A	2	5.6
Parental Education		
Up to High School	10	27.8
Education		
Non-Academic Degree	13	36.1
Academic Degree	11	30.6
Other	2	5.6
	Time 1 M(SD)	Time 2 M(SD)
Age (months)	56.4(9)	62.4(9)
AIM Impact Score	95.43(28.95)	92.11(26.63)
AIM Frequency Score	120.66(24.24)	114.5(25.47)
AIM Communication	36.19(11.55)	33.28(12.17)
AIM Peer interaction	21.85(6.92)	20.77(6.2)
AIM Social Reciprocity	24.07(6.68)	24.94(7.04)
AIM Repetitive Behavior	41.2(13.16)	39.19(12.95)
AIM Atypical Behavior	30.97(7.64)	28.86(7.74)
AIM Total Score	214.38(46.73)	205.47(49.09)
VABS Communication*	70.61(17.5)	70.22(17.16)
VABS Socialization*	72.03(11.01)	71.3(10.28)
VABS Daily Living Skills*	77.36(12.8)	75.69(10.97)
VABS Motor*	76.58(13)	77.28(12.12)
VABS Total Score*	72.47(11.29)	71.5(10.41)

AIM Total score is on a scale of 82–410, AIM Impact and Frequency scores are on a scale of 41–205. Higher scores indicate higher symptom severity

\*Standardized scores (M = 100, SD = 15)

VABS total score as the dependent variable and the AIM total score as the independent variable. The second model employed the VABS total score as the dependent variable and the AIM *Frequency* and *Impact* scores as independent variables. Both models included parent income and education levels as covariates.

MLM was chosen to account for the temporal dependency between observations from the same subject across multiple time points. Due to the limited number of observations, only one random effect could be included. To capture the potential variability in the effect of AIM scores between subjects, a random slope for AIM scores by subject was incorporated. For the second model with *Frequency* and *Impact* scores, including random slopes for either variable yielded similar results. Hence, only the model with a random slope for *Frequency* is reported.

To assess the associations between adaptive functioning and autism symptom sub-domains, two-tailed Pearson correlation tests were performed between the VABS total score and the AIM symptom sub-domain scores. Correlations were calculated separately for time 1 and time 2. The strength of the correlations was described using Cohen's convention (Cohen, 1988).

#### Results

#### **Sample Characterization**

Table 1 presents baseline demographics and clinical characterization of the sample.

#### **Multi Linear Models**

#### Model 1 - AIM Total Score

Based on the results from the mixed linear model, there was a significant negative effect of the AIM total score on the VABS total score (estimate = -7.24, p < .001), suggesting that higher levels of autism symptoms were associated with lower levels of adaptive functioning. The interaction between Timepoint and AIM total was not significant (estimate = 0.48, p = .641), indicating that the effect of autism symptoms on adaptive functioning did not significantly change over time.

Regarding the covariates, parent education level was not significantly associated with adaptive functioning, with estimates of 2.63 (p=.302) for no or high school education, -2.29 (p=.502) for other education levels, and -0.01 (p=.997) for under academic education levels, compared to the reference group. Parent income level also did not significantly predict adaptive functioning, with estimates of 0.85 (p=.739) for low income and 0.20 (p=.912) for medium income, compared to the reference group.

#### Model 2 – AIM Frequency and Impact

Based on the mixed linear model results, there was a significant negative effect of the AIM *frequency* score on the VABS total score (estimate = -8.54, p < .001). This indicates that higher levels of autism symptoms frequency, as measured by the AIM *frequency* score, were associated with lower levels of adaptive functioning, as assessed by the VABS total score. The interaction between Timepoint and AIM *Frequency* was not significant (estimate = 0.48, p = .721), suggesting that the effect of autism symptoms frequency and impact on adaptive functioning did not significantly change over time.

The AIM *Impact* score was not significantly associated with adaptive functioning (estimate = 0.56, p = .753), nor was the interaction between the AIM *Impact* score and timepoint (estimate = -0.46, p = .750).

Regarding the covariates, children of parents with up to high school level education had significantly higher VABS total scores compared to the reference group (estimate = 6.73, p = .011). Other parental education levels, including no academic education, were not significantly associated with adaptive functioning. Income level did not significantly predict adaptive functioning, with estimates of -3.57 (p = .180) for low income and 2.08 (p = .252) for medium income, compared to the reference group.

#### **Bivariate Correlations**

AIM symptom sub-domains significantly negatively correlated with VABS total scores at both time points, with effect sizes ranging between moderate-large: communication (r=-.528, p-0.002; r=-.765, p=.000), peer interaction (r=-.509, p=.002; r=-.590, p=.000), and repetitive behavior (r=-.398, p=.018; r=-.462, p=.005). Social reciprocity trended toward a negative correlation at time 1 (r=-.354, p=.055) and reached significance at time 2 with a large effect size (r=-.690, p=.000). Atypical behavior did not significantly correlate with the VABS total score at time 1 (r=-.275, p=.109), but did at time 2 with a moderate effect size (r=-.454, p=.005).

## Discussion

The findings of the current study demonstrate a significant negative relationship between autism symptomatology and adaptive functioning as per parent-report, such that higher levels of autism symptoms were associated with lower adaptive behavior skills. The findings also showed a negative association between autism symptoms' *frequency* and adaptive functioning, such that a higher frequency of symptoms was associated with lower adaptive skills. Both associations remained stable over time. In contrast, the *impact* scores for autism symptoms were not significantly related to adaptive skills. When examining the associations between adaptive functioning and autism symptom sub-domains, the associations became stronger at the second time point. Moreover, the associations between adaptive functioning and symptoms belonging to criteria A (i.e., social communication) were found to be more prominent than the link with criteria B (i.e., RRBs).

Previous research has found conflicting results regarding the association between adaptive functioning and general symptom severity (Szatmari et al., 2015; Georgiades et al., 2014; Lord et al., 2015). The common explanation for this relationship is that the expression of symptoms inhibits children's ability to use naturalistic settings as learning opportunities for the acquisition of adaptive skills (Franchini et al., 2018; Tillmann et al., 2019). Some researchers suggest that the lack of appropriate adaptive skills creates the need for children to use RRB symptoms for self-regulatory purposes (Wolff et al., 2014; Leekam et al., 2011). These two explanations are not mutually exclusive; there might be a certain reciprocal relationship between these two constructs. Our findings also indicate a stronger association over time, which may be due to the interactive developmental influence (i.e., cascading effects) they have on each other (Leekam et al., 2011). Another aspect to consider when thinking about this relationship over time is the change in environmental expectations regarding adaptive behavior. As children grow up, there are greater expectations and demands for adequate adaptive skills (Koller & Georgiades, 2019; APA, 2013), which may affect the longitudinal interplay between symptoms and adaptive functioning.

Another question we explored is whether different domains of symptoms relate to adaptive functioning in different ways. In line with previous studies (Franchini et al., 2018; Tillmann et al., 2019), we found social communication symptoms to be more highly related to adaptive functioning than RRBs, a trend that became stronger over time. While there is a certain agreement that deficits in social communication have the potential to hinder the development of adaptive functioning, the interaction between RRBs and adaptive functioning is not fully understood. Independent from adaptive functioning, the knowledge of the possible functions and underlying mechanisms of RRBs is still limited (Berry et al., 2018). While RRBs may interfere with children's development, they may also serve functional purposes (Leekam et al., 2011). Further research is needed to fully understand the ways in which RRBs and adaptive functioning affect the development of each other over time. For RRBs, our findings indicate a stronger correlation between adaptive functioning and repetitive behavior than with atypical behavior. This is in line with previous work (Troyb et al., 2016; Wolff et al., 2014), strengthening the notion that different kinds of RRBs interact with adaptive functioning in different ways.

To the best of our knowledge, this is the first study to examine parent-report *frequency* and *impact* of autism symptoms in association with adaptive functioning. Our findings suggest that, for the whole sample, *frequency* of symptoms is more closely related to adaptive functioning than their impact. This finding is somewhat counter-intuitive, considering that the *impact* of symptoms specifically relates their impact on the child's functioning. Some evidence indicates that there are symptoms that are frequent but have minimal impact on daily functioning, while other symptoms may be infrequent while leading to significant functional impairment (Palermo et al., 2008). This raises the possibility that the impact sub-scale is more reflective of the perception parents have regarding the impact of their child's symptoms that may not necessarily correspond with the child's actual adaptive functioning. Though asking about the impact of a symptom on child's everyday functioning, parents may report on different aspects of functioning, such as emotional functioning, or may be affected by the impact the symptom has on family functioning. Reports on the *frequency* of symptoms may involve less interpretation by parents, offering a more objective measure of symptom expression. Another possible explanation is that symptoms have an accumulative effect on adaptive functioning, causing their *frequency* of occurrence to have a larger effect than their impact at a single time point. For instance, setting up toys in a certain fashion may not be perceived as disturbing to everyday functioning as it occurs, but when a child persists in doing so it may inhibit their ability to play with others, learn new skills and develop adaptive behavior. In contrast, when a child bangs their head against the wall, the symptom has an obvious effect on their current everyday functioning, but if this does not occur often it may not disturb their learning of adaptive skills. This explanation considers the developmental aspect of adaptive functioning, viewing symptoms not only as disturbances to the use of adaptive skills, but as an interference to the learning process of adaptive behaviors (Franchini et al., 2018; Tillmann et al., 2019).

## Limitations

Our study has several limitations. Firstly, our findings are from a small pilot sample, and a larger sample is needed to better establish the findings. Moreover, we conducted multiple correlational analyses, which may increase the potential for type 1 error. In addition, the sample size did not allow for an analysis of individual trajectories, which may reveal differential patterns of the relationship between adaptive functioning and symptomatology in children with varying phenotypes. Secondly, this study only examines the association between adaptive functioning and symptomatology, without considering other variables that may affect this relationship (e.g., intellectual abilities, behavioral problems, services received, etc.). Lastly, our findings are based on parent-report measures, therefore reflective of symptoms and adaptive skills as perceived by parents. Though considered less objective, we believe parent-report provides complimentary information regarding the child's clinical presentation throughout settings, offering good external validity to the findings.

#### **Implications and Future Directions**

This study examined the association between adaptive functioning and symptomatology, alongside the relative importance of social communication in this association. This is the first study to date to examine the relationship of *frequency* and *impact* of symptoms with adaptive functioning, providing new information regarding the different facets of symptoms expression that can be considered in relation to adaptive functioning. Our findings are another stepping stone towards a more nuanced understanding of the relationship between these two constructs, both having a significant effect on child and family's functioning and well-being (Hyman et al., 2020; Picardy et al., 2018; Kuhlthau et al., 2010; Gardiner & Iarocci, 2015).

Future research should examine the associations found in this study in a larger sample, tracking the developmental trajectories at both the group and individual level. Understanding the associations of adaptive functioning and symptomatology in distinct groups of children may promote the timely delivery of targeted interventions that support children in a more personalized manner. Attention should also be given to the concepts of *frequency* and *impact* as different aspects of symptom expression that may have differential influences on the development of adaptive functioning in different groups of children.

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#### Declarations

Conflict of interest All authors report no conflict of interest.

## References

- Alvares, G. A., Bebbington, K., Cleary, D., Evans, K., Glasson, E. J., Maybery, M. T., Pillar, S., Uljarević, M., Varcin, K., Wray, J., & Whitehouse, A. J. O (2020). The misnomer of 'high functioning autism': Intelligence is an imprecise predictor of functional abilities at diagnosis. *Autism*, 24(1), 221–232. https://doi. org/10.1177/1362361319852831.
- American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders: DSM-5 (5th ed.). American Psychiatric Association.
- Berry, K., Russell, K., & Frost, K. (2018). Restricted and repetitive behaviors in Autism Spectrum Disorder: A review of Associated features and presentation across clinical populations. *Current Developmental Disorders Reports*, 5(2), 108–115. https://doi. org/10.1007/s40474-018-0139-0.
- Chatham, C. H., Taylor, K. I., Charman, T., Liogier D'ardhuy, X., Eule, E., Fedele, A., Hardan, A. Y., Loth, E., Murtagh, L., del Valle Rubido, M., Caceres, S. J., Sevigny, A., Sikich, J., Snyder, L., Tillmann, L., Ventola, E. A., Walton-Bowen, P. E., Wang, K. L., Willgoss, P. P., T., & Bolognani, F. (2018). Adaptive behavior in autism: Minimal clinically important differences on the Vineland-II. Autism Research, 11(2), 270–283. https://doi.org/10.1002/ aur.1874.
- Chiang, H. M., & Wineman, I. (2014). Factors associated with quality of life in individuals with autism spectrum disorders: A review of literature. *Research in Autism Spectrum Disorders*, 8(8), 974– 986. https://doi.org/10.1016/j.rasd.2014.05.003.
- Cohen, J. (1988). The effect size. Statistical power analysis for the behavioral sciences, 77–83.
- Farley, M. A., McMahon, W. M., Fombonne, E., Jenson, W. R., Miller, J., Gardner, M., Block, H., Pingree, C. B., Ritvo, E. R., Ritvo, R. A., & Coon, H. (2009). Twenty-year outcome for individuals with autism and average or near-average cognitive abilities. *Autism Research*, 2(2), 109–118. https://doi.org/10.1002/aur.69.
- Franchini, M., Zöller, D., Gentaz, E., Glaser, B., De Wilde, H. W., Kojovic, N., Eliez, S., & Schaer, M. (2018). Early adaptive functioning trajectories in preschoolers with autism spectrum disorders. *Journal of Pediatric Psychology*, 43(7), 800–813. https:// doi.org/10.1093/jpepsy/jsy024.
- Gabriels, R. L., Cuccaro, M. L., Hill, D. E., Ivers, B. J., & Goldson, E. (2005). Repetitive behaviors in autism: Relationships with associated clinical features. *Research in Developmental Disabilities*, 26, 169–181. https://doi.org/10.1016/j.ridd.2004.05.003.
- Gardiner, E., & Iarocci, G. (2015). Family quality of life and asd: The role of child adaptive functioning and behavior problems. *Autism Research*, 8(2), 199–213. https://doi.org/10.1002/aur.1442.
- Georgiades, S., Boyle, M., Szatmari, P., Hanna, S., Duku, E., Zwaigenbaum, L., Bryson, S., Fombonne, E., Volden, J., Mirenda, P., Smith, I., Roberts, W., Vaillancourt, T., Waddell, C., Bennett, T., Elsabbagh, M., Thompson, A., & Pathways in ASD Study Team. (2014). Modeling the phenotypic Architecture of autism symptoms from time of diagnosis to Age 6. *Journal of Autism* and Developmental Disorders, 44(12), 3045–3055. https://doi. org/10.1007/s10803-014-2167-x.
- Georgiades, S., Bishop, S. L., & Frazier, T. (2017). Editorial Perspective: Longitudinal research in autism – introducing the concept of 'chronogeneity'. *Journal of Child Psychology and Psychiatry*

and Allied Disciplines, 58(5), 634–636. https://doi.org/10.1111/jcpp.12690.

- Georgiades, K., Russell, C., Kata, A., Lakkadghatwala, R., & Lee, S. (2017a). Socio-Demographic Questionnaire [V.5].
- Hyman, S. L., Levy, S. E., Myers, S. M., Children, O. N., & Disabilities, W. (2020). Identification, evaluation, and management of children with autism spectrum disorder. *Pediatrics*, 145(1). https://doi.org/10.1542/peds.2019-3447.
- Kanne, S. M., Mazurek, M. O., Sikora, D., Bellando, J., Branum-Martin, L., Handen, B., Katz, T., Freedman, B., Powell, M. P., & Warren, Z. (2014). The autism impact measure (AIM): Initial development of a new tool for treatment outcome measurement. *Journal of Autism and Developmental Disorders*, 44(1), 168–179. https://doi.org/10.1007/s10803-013-1862-3.
- Kata, A., McPhee, P. G., Chen, Y-J., Zwaigenbaum, L., Singal, D., Roncadin, C., Bennett, T., Carter, M., DiRezze, B., Drmic, I., Duku, E., Fournier, S., Frei, J., Gentles, S., Georgiades, K., Hanlon-Dearman, A., Hoult, L., Kelley, E., Koller, J., de Kraus, O., Lai, J., Mahoney, B., Mesterman, R., Ng, O., Robertson, S., Rosenbaum, P., Salt, M., Zubairi, M., & Georgiades, S. (2024). The Pediatric Autism Research Cohort (PARC) Study: protocol for a patient-oriented prospective study examining trajectories of functioning in children with autism. *BMJ Open*, *14(4)*https://doi. org/10.1136/bmjopen-2023-083045.
- Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2015). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, 20(4), 442–462. https://doi.org/10.1177%2F1362361315588200.
- Kim, S. H., Macari, S., Koller, J., & Chawarska, K. (2016). Examining the phenotypic heterogeneity of early autism spectrum disorder: Subtypes and short-term outcomes. *Journal of Child Psychology* and Psychiatry and Allied Disciplines, 57(1), 93–102. https://doi. org/10.1111/jcpp.12448.
- Kim, G. Y., SoHyun, L., Tuck, K. N., & Martinez, J. R. (2024). Effects of embedding special interest area in instruction on the engagement and out-of-seat behaviors of children with autism spectrum disorder. *Focus on Autism and Other Developmental Disabilities*. https://doi.org/10.1177/10883576241232894.
- Koller, J., & Georgiades, S. (2019). Letter to the Editor: The balance between demands and capacity in autism. *Developmental Medicine and Child Neurology*.
- Koziarz, F., Roncadin, C., Kata, A., Duku, E., Cauwenbergs, A., Mahoney, W., Di Rezze, B., Anderson, C., Drmic, I., Eerkes, J., Dekker, K., Georgiades, K., Hoult, L., de Camargo, K., Ng, O., Rosenbaum, O., Mesterman, P., Gentles, R., Robertson, S. J., & Georgiades, S., S (2021). Investigating the associations between Child autistic symptoms, socioeconomic context, and Family Life: A pilot study. *Frontiers in Rehabilitation Sciences*, 2(December), 1–7. https://doi.org/10.3389/fresc.2021.748346.
- Kuhlthau, K., Orlich, F., Hall, T. A., Sikora, D., Kovacs, E. A., Delahaye, J., & Clemons, T. E. (2010). Health-Related Quality of Life in children with autism spectrum disorders: Results from the autism treatment network. *Journal of Autism and Developmental Disorders*, 40(6), 721–729. https://doi.org/10.1007/ s10803-009-0921-2.
- Leekam, S. R., Prior, M. R., & Uljarevic, M. (2011). Restricted and repetitive behaviors in autism spectrum disorders: A review of research in the last decade. *Psychological Bulletin*, 137(4), 562– 593. https://doi.org/10.1037/a0023341.
- Lord, C., Bishop, S., & Anderson, D. (2015). Developmental trajectories as autism phenotypes. *American Journal of Medical Genetics Part C: Seminars in Medical Genetics*, 169(2), 198–208. https:// doi.org/10.1002/ajmg.c.31440.
- Mazurek, M. O., Carlson, C., Baker-Ericzén, M., Butter, E., Norris, M., & Kanne, S. (2020). Construct validity of the Autism Impact

measure (AIM). Journal of Autism and Developmental Disorders, 50(7), 2307–2319. https://doi.org/10.1007/s10803-018-3462-8.

- Mazurek, M. O., Carlson, C., Baker-Ericzén, M., Butter, E., Norris, M., Barr, C., & Kanne, S. (2020b). The Autism Impact measure (AIM): Examination of sensitivity to change. *Autism Research*, *13*(11), 1867–1879. https://doi.org/10.1002/aur.2397.
- Palermo, T. M., Long, A. C., Lewandowski, A. S., Drotar, D., Quittner, A. L., & Walker, L. S. (2008). Evidence-based assessment of health-related quality of life and functional impairment in pediatric psychology. *Journal of Pediatric Psychology*, 33(9), 983–996.
- Picardi, A., Gigantesco, A., Tarolla, E., Stoppioni, V., Cerbo, R., Cremonte, M., Alessandri, G., Lega, I., & Nardocci, F. (2018). Parental Burden and its correlates in families of children with Autism Spectrum disorder: A Multicentre Study with two comparison groups. *Clinical Practice & Epidemiology in Mental Health*, 14(1), 143–176. https://doi.org/10.2174/1745017901814010143.
- Sparrow, S., Cicchetti, D., & Saulnier, C. A. (2016). Vineland adaptive behavior scales- third edition.
- Szatmari, P., Georgiades, S., Duku, E., Bennett, T. A., Bryson, S., Fombonne, E., Mirenda, P., Roberts, W., Smith, I. M., Vaillancourt, T., Volden, J., Waddell, C., Zwaigenbaum, L., Elsabbagh, M., & Thompson, A. (2015). Developmental trajectories of symptom severity and adaptive functioning in an inception cohort of preschool children with autism spectrum disorder. JAMA Psychiatry, 72(3), 276–283. https://doi.org/10.1001/ jamapsychiatry.2014.2463.

- Tillmann, J., San José Cáceres, A., Chatham, C. H., Crawley, D., Holt, R., Oakley, B., Banaschewski, T., Baron-Cohen, S., Bölte, S., Buitelaar, J. K., Durston, S., Ham, L., Loth, E., Simonoff, E., Spooren, W., Murphy, D. G., & Charman, T. (2019). Investigating the factors underlying adaptive functioning in autism in the EU-AIMS Longitudinal European Autism Project. *Autism Research*, *12*(4), 645–657. https://doi.org/10.1002/aur.2081. & the EU-AIMS LEAP group
- Tomaszewski, B., Hepburn, S., Blakeley-Smith, A., & Rogers, S. J. (2020). Developmental trajectories of adaptive behavior from toddlerhood to middle childhood in autism spectrum disorder. *American Journal on Intellectual and Developmental Disabilities*, 125(3), 155–169.
- Troyb, E., Knoch, K., Herlihy, L., Stevens, M. C., Chen, C. M., Barton, M., Treadwell, M., & Fein, D. (2016). Restricted and repetitive behaviors as predictors of Outcome in Autism Spectrum disorders. *Journal of Autism and Developmental Disorders*, 46(4), 1282–1296. https://doi.org/10.1007/s10803-015-2668-2.
- Wolff, J. J., Botteron, K. N., Dager, S. R., Elison, J. T., Estes, A. M., Gu, H., Hazlett, H. C., Pandey, J., Paterson, S. J., Schultz, R. T., Zwaigenbaum, L., Piven, J., & Network, I. B. I. S. (2014). Longitudinal patterns of repetitive behavior in toddlers with autism. *Journal of Child Psychology and Psychiatry*, 55(8), 945–953.

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